

Help-seeking intention in an adult population with obsessive-compulsive disorder

(OCD): predictors and barriers in South Africa

by

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DECLARATION

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ABSTRACT

Introduction: Obsessive-compulsive disorder (OCD) is associated with significantly impaired functioning, psychological distress, and reduced quality of life. Despite the availability of evidence-based treatments, a large percentage of individuals with OCD fail to seek help for their condition or delay help-seeking for many years. Although variables associated with OCD help-seeking have been identified internationally, patterns of help-seeking for OCD have not yet been described in South Africa, a developing country with many mental health service challenges.

Aim: Using the health belief model (HBM) as a framework, the aims of this study were two-fold: first, to investigate whether HBM constructs significantly predict help-seeking intention among a group of South African adults with OCD, and second, to determine the most endorsed barriers to help-seeking for OCD in this sample.

Methods: Fifty adult participants (n=50) with a lifetime primary diagnosis of OCD based on the Structured Clinical Interview for the DSM-5 (SCID-5) were recruited to participate. Participants subsequently completed a comprehensive online survey to assess the following HBM constructs: 1) socio-demographic characteristics, 2) OCD symptom severity, 3) treatment barriers, 4) perceived treatment benefits, 5) self-efficacy, and 6) help-seeking intention. Multiple linear regression analysis was used to establish whether HBM constructs significantly predict help-seeking intention. Descriptive statistics were calculated to determine the most endorsed barriers to help-seeking. The Statistical Package for Social Sciences (SPSS) version 27 was used to analyse the data.

Results: The findings suggested that 42.6% of variance in help-seeking intention can be explained by the six HBM constructs ($R^2 = 0.426$, $F(7,42) = 4.45$ $p < 0.01$). Of all predictor variables, perceived treatment benefits was the only significant predictor of help-seeking

intention ($B=1.37$, $t(42)= 5.16$, $p<0.01$). In terms of help-seeking barriers, 36% of the sample endorsed wanting to handle the problem independently as a highly significant barrier, followed by concerns about treatment (endorsed by 26% of the sample), then affordability (22% of the sample), and finally embarrassment and shame factors (20% of the sample).

Conclusion: This is the first study to investigate help-seeking patterns among South African adults with OCD. The results lend partial support for the utility of HBM constructs in predicting help-seeking intention, with perceived treatment benefits as the only significant predictor of help-seeking intention in this setting. Psychoeducation and mental health literacy programmes may be useful in increasing public appreciation of the benefits of OCD treatment, and to mitigate key help-seeking barriers. Studies with a qualitative angle, revealing a more in-depth understanding of the use of services from the patient's perspective, would complement these findings.

Keywords: Obsessive-compulsive disorder, help-seeking, predictors, barriers, health belief model, South Africa, mental health service-use

OPSOMMING

Inleiding: Obsessief-kompulsiewe steuring (OKS) is geassosieer met 'n beduidende inperking in funksionering, sielkundige distres, en verminderde lewenskwaliteit. Ten spyte van die beskikbaarheid van bewysgebaseerde behandeling, is daar 'n groot persentasie van individue met OKS wat nie hulp vir hulle toestand soek nie of hulpsoek oor baie jare uitstel. Hoewel die veranderlikes wat met hulpsoek verband hou geïdentifiseer is in internasionale studies, is patrone van hulpsoek nog nie in Suid-Afrika – 'n ontwikkelende land met vele geestesgesondheidsuitdagings – beskryf nie.

Doel: Hierdie studie het die “health belief model” (HBM) gebruik as raamwerk. Die doelstellings van hierdie studie was tweeledig: eerstens, om vas te stel of die konstrakte van HBM die intensie om hulp te soek kan voorspel in 'n groep volwassenes met OKS in Suid-Afrika, en tweedens, om vas te stel wat die mees onderskryfde hindernisse tot hulpsoek vir OKS in hierdie steekproef was.

Metodes: Vyftig volwasse deelnemers ($n = 50$) met 'n lewenslange primêre diagnose van OCD gebaseer op die “Structured Clinical Interview for the DSM-5 (SCID-5)” is gewerf om deel te neem. Deelnemers het daarna 'n uitgebreide aanlyn-opname oor die volgende HBM-konstrukte voltooi: 1) sosio-demografiese eienskappe, 2) erns van OKS-simptome, 3) waargenome behandelingshindernisse, 4) waargenome behandelingsvoordele, 5) selfdoeltreffendheid, sowel as 6) die voorneme om hulp te soek. Veelvuldige lineêre regressie-analise is gebruik om vas te stel of HBM-konstrukte hulpsoek-voorneme in hierdie steekproef kan voorspel. Beskrywende statistieke is bereken om die mees onderskryfde hindernisse tot hulpsoek te bepaal. Die statistiese pakket vir sosiale wetenskappe (SPSS) weergawe 27 is gebruik om die data te ontleed.

Resultate: Die bevindinge dui daarop dat 42,6% van die variansie in hulpsoek-voornemens deur die ses HBM-konstrukte verklaar kan word ($R^2 = .426$, $F(7,42) = 4.45$, $p < 0.01$). Van alle voorspeller veranderlikes was waargenome behandelingsvoordele die enigste beduidende voorspeller van hulpsoek-voorneme ($B = 1,37$, $t(42) = 5.16$, $p < 0.01$). Wat die hulpsoek-hindernisse betref, het 36% van die steekproef aangedui dat hulle die probleem onafhanklik wil hanteer as 'n uiters belangrike hindernis, gevolg deur kommer oor behandeling (wat deur 26% van die steekproef goedgekeur is), en dan bekostigbaarheid (22% van die steekproef), en uiteindelik verleentheid- en skande- faktore (20% van die steekproef).

Gevolgtrekking: Dit is die eerste studie wat hulpsoekpatrone onder Suid-Afrikaanse volwassenes met OKS ondersoek het. Die resultate verleen 'n gedeeltelike ondersteuning vir die nut van HBM-konstrukte in die voorspelling van hulpsoek-voorneme, met waargenome behandelingsvoordele die enigste beduidende voorspeller van hulpsoek-voorneme in hierdie konteks. Psigo-opvoeding en geestesgesondheidsgeletterdheidsprogramme kan nuttig wees om die publiek se waardering vir die voordele van OCD-behandeling te verhoog en om hulpsoek-hindernisse, te verminder. Studies met 'n kwalitatiewe invalshoek, wat 'n meer diepgaande begrip van die gebruik van dienste vanuit die pasiënt se perspektief kan openbaar, sal hierdie bevindings aanvul.

Slutelwoorde: Obsessief-kompulsiewe steuring, hulpsoek-voorneme, voorspellers, hindernisse, 'health belief model', Suid-Afrika, gebruik van geestesgesondheidsdienste

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GLOSSARY OF TERMS

Adult	An individual who is 18 years or older.
CBT	Cognitive behavioural therapy focusing on the relationship between thoughts, feelings, and behaviours.
Compulsions	Mental acts or behaviours performed in response to obsessions in order to reduce distress.
ERP	A CBT treatment technique involving exposure to feared stimuli while withholding unhelpful responses (i.e., compulsions).
Formal help-seeking	The process of seeking assistance from professional services.
Help-seeking	A broad concept involving cognitive or behavioural efforts to solve a problem by obtaining assistance from a third party.
Help-seeking intention	A cognitive state involving a sense of motivation to obtain help for a problem.
Impairment	A state of diminished physical or psychological functioning.
Obsessions	Repetitive and intrusive thoughts, urges, or impulses that cause clinical distress.
OCD	A debilitating psychiatric disorder characterised by the presence of obsessions and compulsions.

ABBREVIATIONS

ATSPPH	Attitudes Towards Seeking Professional Psychological Help
ATSPPH-SF	Attitudes Towards Seeking Professional Psychological Help-Short Form
BACE	Barriers to Access to Care Evaluation
BRICS	Brazil, Russia, India, China, and South Africa
I-CBT	Internet-based cognitive-behavioural therapy
CBT	Cognitive behavioural therapy
CGI-I	Clinical global Impressions-Improvement Scale
DSM	Diagnostic and Statistical Manual of Mental Disorders
DUI	Duration of untreated illness
ERP	Exposure response prevention
FOCI	Florida Obsessive Compulsive Inventory scale
GP	General practitioner
GSES	General Self-efficacy Scale
HBM	Health belief model
MRC	Medical Research Council of South Africa
NCS-R	National Comorbidity Survey Replication
NHRPL	National Health Reference Price List
OCD	Obsessive-compulsive disorder
OCRDs	Obsessive-compulsive and related disorders
SCID-5	Structured clinical interview for the DSM-5
SES	Socio-economic status
SPSS	The Statistical Package for Social Sciences
SU	Stellenbosch University

TPB	Theory of planned behaviour
TRA	Theory of reasoned action
USA	United States of America
WHO	World Health Organization
WMH-ICS	World Mental Health International College Student
Y-BOCS	Yale-Brown Obsessive Compulsive Scale
Y-BOCS-SR	Yale-Brown Obsessive Compulsive Scale-Self Report

Chapter 1: Introduction

For many years, obsessive-compulsive disorder (OCD) was believed to be a rare disorder. However, recently, it has shown to affect 2% to 3% of the adult population, and is known to be a primary contributor to the global burden of disease (Stein et al., 2019). Despite this, OCD is consistently under-represented in mental health settings (Abramowitz, Blakey, Reuman, & Buchholz, 2018) as well as trivialised in the media and popular culture – typically depicted as a collection of comedic, uptight personality traits (Cefalu, 2009). Thus, the gravity of the condition and the associated level of impairment is often not recognised. Exploration of the experiences and challenges associated with OCD diagnosis and treatment is called for, and may make a meaningful contribution to more accurate representations of the disorder. In this chapter, I introduce the reader to OCD and outline its impact and outcomes, followed by a brief discussion of treatment and help-seeking challenges. Thereafter, I present my research rationale, aims and hypothesis, before concluding the chapter with an overview of the scope of the thesis.

1.1. Introducing OCD

1.1.1. The disorder defined. OCD is defined by the diagnostic and statistical manual 5th edition (DSM-5) by the presence of one or more or of the following:

- I. **obsessions:** persistent and intrusive thoughts, urges, or mental images that cause distress and/or

- II. **compulsions:** repetitive rituals involving behaviours or mental acts performed in response to obsessions, with the goal of neutralising obsessions and /or alleviating anxiety (American Psychiatric Association, 2013).

A diagnosis of OCD indicates that obsessions and/or compulsions are causing clinically significant distress, which is important given that some level of obsessive thinking is not uncommon in the general population (Stein et al., 2019). A number of factors differentiate obsessions from routine obsessional thinking, namely a) obsessions are *involuntary* and uncontrolled, often triggered by environmental cues, b) they are *inconsistent* with an individual's value system, and c) they are rejected and *resisted* against, thus activating compulsions as a response to counteract or “handle” the fear and distress associated with obsessions (Abramowitz & Siqueland, 2013). The motivation to perform a compulsion is often fuelled by fear that catastrophic consequences might occur if a specific behavioural or mental action is not taken (Abramowitz & Jacoby, 2014). The most common form of compulsion is observable and ritualised, i.e., repetitive behaviours that are recurring and rule-bound. An example would be washing hands while counting to a “magic number” in response to an obsessional fear of contamination. Covert, non-ritualised compulsions also exist, for example, distraction strategies including avoidance in response to obsessive thoughts, although these compulsions are less observable and often are not bound by rules (Abramowitz & Jacoby, 2014). Both forms of compulsions are typically performed *in reaction* to obsessions to minimise distress or prevent feared consequences.

Although OCD is characterised by a heterogeneous presentation and manifests differently for each individual, a number of common themes relating to obsessions and compulsions have emerged (Abramowitz & Siqueland, 2013). Typical obsessional themes include worries about hygiene and contamination, fears about injury or damage to self or others, unacceptable sexual, immoral, or violent thoughts, and concerns about orderliness.

Common compulsions include cleaning and washing, checking, counting, praying, and mental rituals (Walitza et al., 2011). A critical discussion of the conceptualisation of OCD – including diagnostic debates – is explored further in chapter two.

1.1.2. Impact. OCD is associated with significant personal, social and economic costs, and with placing a heavy burden not only on patients, but also on their loved ones, employers, and wider social systems (Mayerovitch et al., 2003). Research shows that OCD has a similar impact on quality of life as does a diagnosis of schizophrenia, despite receiving less attention from policy-makers and researchers (Akyurek, Sahadet Sezer, Kaya, & Temucin, 2019). The significant level of impairment associated with OCD is largely a result of the amount of *time* spent on obsessions and compulsions, coupled with *avoidance* of daily activities that might serve as triggers (American Psychiatric Association, 2013). Although an OCD diagnosis requires that obsessions or compulsions should consume at minimum one hour per day, studies show that obsessions can take up an average of up to six hours per day, and compulsions an average of four and a half hours per day (Garcia-Soriano, Rufer, Delsignore, & Weidt, 2014). Thus, for patients with severe OCD, the condition may consume their whole day (Srivastava, Bhatia, Thawani, & Jhanjee, 2011). Furthermore, a key feature of OCD involves avoiding situations, spaces, or people that might trigger obsessions and compulsions (American Psychiatric Association, 2013). For example, individuals with a fear of contamination would naturally curtail social interactions or public places which may be perceived as “dirty”, such as offices or bathrooms. This level of avoidance can significantly impede occupational role performance, and research has shown that OCD is associated with approximately 46 days absence from work over a 12-month period (Stein et al., 2019). Unsurprisingly, the condition creates a difficult emotional burden for patients, with obsessions typically evoking negative feelings such as anger, sadness, hopelessness, and disgust (Kohler, 2017; Kohler, Coetzee, & Lochner, 2018). In addition to the challenges of

coping with the condition itself, OCD is characterised by significant psychiatric comorbidity. The National Comorbidity Survey Replication (NCS-R) demonstrated that 90% of individuals diagnosed with OCD also met the criteria for another psychiatric disorder, the most common of which included mood disorders, anxiety disorders, and substance-use disorders (Ruscio, Stein, Chiu, & Kessler, 2010). In summary, individuals with OCD may be consumed by obsessing and/or performing compulsive rituals, avoiding the business of daily living in order to escape triggers, and being challenged by negative and distressing emotions, as well as comorbidities. Needless to say, this level of disturbance has been shown to impair self-esteem, quality of life, occupational performance, and interpersonal relationships (Franklin & Foa, 2011). Thus, the impact of the disorder is clearly multi-faceted and potentially devastating.

1.1.3. Course and treatment. OCD usually follows either a chronic or episode course (Sharma & Math, 2019). In chronic cases, symptoms are persistent and ever-present, although they may wax and wane over time – usually increasing in severity during periods of stress (Abramowitz & Siqueland, 2013). In episodic cases, which are relatively rare, symptoms are only present for a period of time (Sharma & Math, 2019). If untreated, OCD generally becomes chronic and significantly impairing (Abramowitz & Siqueland, 2013).

Considerable progress has been made in the realm of OCD treatment in the last three decades, with the development of evidence-based psychotherapeutic and pharmacological treatments (Abramowitz et al., 2018). Moreover, at least half of patients who receive treatment will experience long-term remission as a result (Sharma & Math, 2019). A shorter duration of illness with early treatment consistently correlates with higher remission rates and more positive outcomes (Albert et al., 2019; Franklin & Foa, 2011; Sharma & Math, 2019), illustrating the importance of early diagnosis and intervention.

Despite these treatment advancements, the majority of individuals with OCD do not reach out for professional help and remain untreated, or delay the help-seeking process for many years (Besiroglu & Agargun, 2006). Global trends demonstrate that approximately 40% to 90% of individuals with OCD fail to seek advice for their condition (Albert et al., 2019), contributing to what has been termed the “OCD help-seeking dilemma” (Belloch et al., 2008, p.8). International research indicates that factors fuelling this dilemma are multi-faceted, and exist on both structural and psychological levels (Garcia-Soriano et al., 2014). Further research is necessary in order to understand help-seeking patterns for OCD in South Africa.

Treatment interventions for OCD fall into the category of *formal help*, involving assistance from professionals who are qualified to provide assistance and treatment – including medical doctors, psychologists, psychiatrists, counsellors, and other health practitioners (Rickwood & Thomas, 2012). *Informal help*, on the other hand, entails support from personal relationships and networks, such as friends or family (Rickwood & Thomas, 2012). Although informal support plays an important role in OCD outcomes (Steketee, 1993), formal help has garnered the most empirical support (Franklin & Foa, 2011; Hirschtritt, Bloch, & Mathews, 2017; Kellner, 2010; Stein, 2013), and therefore was selected to be the focus of this study. A more comprehensive conceptual overview of help-seeking processes is discussed in chapter two.

1.2. Research rationale

A significant treatment gap exists for OCD largely due to delayed or absent help-seeking (Hirschtritt et al., 2017). A number of international studies suggest that a complex combination of factors influence the process of seeking formal help for the condition (e.g., Belloch, Del Valle, Morillo, Carrió, & Cabedo, 2008; Besiroglu, Cilli, & Askin, 2004; Williams, Marques, Leblanc, & Turkheimer, 2012). However, to my knowledge, the problem

of help-seeking for OCD has not been examined in South Africa, where a number of complex service-use challenges exist. Such challenges involve system-level obstacles in particular, including problems of affordability, geographical disparities in resources, and a dual-sector health system characterised by complex burden of disease (Docrat, Besada, Cleary, Daviaud, & Lund, 2019; Jack et al., 2014; Petersen et al., 2016). In this way, international findings focusing on help-seeking and service use for OCD should be interpreted with caution, and should not necessarily be translated to our local system.

In order to investigate this neglected area of research, I explored a range of academic databases – including PubMed; SAGEjournals; ResearchGate; ScienceDirect; PSYCinfo; South African Journal of Psychiatry, among others – searching the keywords “obsessive-compulsive disorder”, “OCD”, “help”, “formal help”, “treatment”, “help-seeking”, “help-seeking intention”, “help-seeking predictors”, “help-seeking barriers”, “treatment barriers”, “South Africa”, and “adults” in multiple combinations. The search did not yield any studies focusing on help-seeking or treatment-seeking for OCD in South Africa. Thus, this study aims to expand upon the current conversation concerning formal help-seeking for OCD, and contribute to OCD research that is relevant to the challenges that exist within our local context. In order to conceptualise factors that influence the formal help-seeking process, I have drawn on the health belief model (HBM), which presents a number constructs, or health beliefs, that explain processes of engagement with professional health services (Rosenstock, 1974, 1990). The HBM is described in further detail in chapter three.

1.3. Research aims and hypothesis

This study addressed the first research aim:

- To investigate whether HBM constructs significantly predict help-seeking intention among a group of South African adults with OCD.

To attend to the first research aim, the following hypothesis (H1) was tested:

- HBM constructs significantly predict help-seeking intention among a group of South African adults with OCD.

The null hypothesis (H0) was as follows:

- There is no relationship between HBM constructs and help-seeking intention among a group of South African adults with OCD.

In addition, a second research aim was addressed, namely:

- To determine the most endorsed barriers to help-seeking among a group of South African adults with OCD.

In addressing these two aims, the current study endeavoured to generate knowledge about factors that influence individuals in the process of seeking formal help for OCD in South Africa, and to contribute to the absence of literature in this regard.

1.4. Overview of chapters

This thesis consists of six chapters. The first chapter has laid the foundation for the thesis in terms of introducing the reader to information concerning OCD and the research rationale, aims, and hypothesis. The second chapter includes a comprehensive and critical review of literature relevant to the conceptualisation of OCD and help-seeking, from both an international and local perspective. The third chapter describes the theoretical framework that guided the conceptualisation of this research. The fourth chapter outlines the methodological tools involved in the study, including a detailed description of the measurement tools and the data analysis process. In the fifth chapter, study findings are presented. This is followed by the sixth and final chapter which offers an interpretation of the results, a discussion of the

strengths and limitations of the study along with future recommendations, with concluding remarks.

Chapter 2: Literature review

In this chapter I first offer a critical discussion of key concepts relevant to OCD, in order to introduce the reader to some of the controversies and debates surrounding the conceptualisation of the disorder. Thereafter, I provide a conceptual overview of help-seeking processes, before discussing international studies focusing on help-seeking for OCD: highlighting the sources of help that have shown to be effective in treating OCD, and the various factors that influence the OCD help-seeking process. This is followed by a review of relevant South African literature focusing on help-seeking for mental health concerns, demonstrating the paucity of literature focusing on help-seeking for OCD in this setting.

2.1. Understanding OCD: concepts and controversies

2.1.1. Diagnostic debates. The DSM-5 diagnostic criteria outlined in chapter one (and detailed in Appendix 1) represent OCD as a list of symptoms that are neatly delineated into obsessions and compulsions, and with an emphasis on repetitive thoughts and behaviours. Although this level of standardisation and simplification is helpful for diagnostic purposes, it arguably does not fully capture the complexity of the *relationship* between obsessions and compulsions. This misrepresentation is, in part, reinforced by the definition of the disorder involving the “presence of obsessions, compulsions, or both” (American Psychiatric Organization, 2013, p. 237) indicating that obsessions and compulsions may exist independently from one another. In contrast, research examining the phenomenology of OCD has highlighted the intrinsically connected nature of obsessions and compulsions (Abramowitz & Jacoby, 2014; Shafran, 2006). Compulsions occur in order to resist, control,

or minimise obsessions, offering (momentary) relief in the short term, but ultimately exacerbating the intensity of obsessions in the long term, thus maintaining the problem (Abramowitz & Deacon, 2006). Therefore, this research shows that OCD has complex functional features, with obsessions and compulsions reinforcing each other in a cyclical way (Abramowitz & Jacoby, 2014). However, the current description in the DSM-5 does not qualify this, which may lead to incomplete understandings about the functional nature of the condition.

OCD was previously classified as an anxiety disorder in the fourth edition of the DSM due to the central role of anxiety associated with obsessions, as well as the temporary reduction of obsessional anxiety as a result of compulsions (Hollander, 2011). However, the release of the DSM-5 in 2013 marked a shift in the classification of OCD, which was removed from the anxiety disorder class and reclassified under a new diagnostic category of obsessive-compulsive and related disorders (OCDs). In addition to OCD, this chapter includes body dysmorphic disorder, hoarding disorder, trichotillomania (hair-pulling disorder), excoriation (skin-picking) disorder, as well as other specified and unspecified OCDs (American Psychiatric Association, 2013). The novel category was introduced on account of shared clinical features between the OCDs, including genetic etiology, symptoms involving repetitive thoughts and behaviours, and treatment methods (Hollander, 2011). Unsurprisingly, the introduction of this chapter has been the subject of much discussion and debate. Many OCD experts have questioned the commonalities between the OCDs. For example, Monzani, Rijdsdijk, Harris, and Mataix-Cols (2014) highlight that evidence to support the relatedness of genetic risk factors among the OCDs is incomplete and inconsistent. Researchers have also rejected the focus on “repetitive behaviours” as a defining characteristic of the OCDs (American Psychiatric Association, 2013, p.235) due to this diagnostic feature being shared by other mental disorders (such as substance use

disorders and gambling disorder) and on account of this emphasis being insensitive to the nuanced symptomology of many of the OCRDs (Abramowitz & Jacoby, 2014; Abramowitz & Jacoby, 2015). This reflects an important critique of the current diagnostic conceptualisation of OCD in the DSM-5 which also emphasises “repetitive behaviours” (American Psychiatric Organization, 2013, p. 237) in a way that does not adequately account for less observable, non-ritualised forms of compulsions – such as distraction or avoidance strategies – which are also common (Abramowitz & Jacoby, 2014) and play a critical role in the maintenance of obsessional problems. Arguably, the complex and heterogeneous presentation of obsessions and compulsions – and the relationship between them – is important for clinicians to understand and address in treatment, and is not effectively captured in the DSM-5.

2.1.2. Etiology. A number of theories have emerged in the literature to explain the etiology of OCD, with some tensions between paradigms. From a biological perspective, the serotonin hypothesis garnered some support historically due to the role of serotonergic medication in relieving OCD symptoms (Barr, et al., 1992). However, other biological indicators (such as blood) demonstrated a weak relationship between serotonin and OCD pathogenesis, and therefore the serotonin hypothesis was deemed insufficient and abandoned by many researchers (Abramowitz & Siqueland, 2013). More recently, the glutamate hypothesis has received some attention, holding that disruption of the glutamate neurotransmitter – located within the cortical-striatal-thalamocortical (CSTC) circuitry – plays a significant role in the development of OCD (Wu, Hanna, Rosenberg & Arnold, 2013). This hypothesis is based on evidence from neuroimaging studies, gene studies, and animal models (Ting & Feng, 2008), although there are some mixed findings across studies (Abramowitz & Siqueland, 2013). Biological models have been useful in illuminating the different genetic structures and neurotransmitters involved in OCD. However, the complexity

of the nervous system has made it difficult to identify and quantify the exact changes that occur in the brain as a result of OCD-related genes (Schneider, 2019). Further, biological models have been critiqued for being reductionist (Franzblau, Kanadianian, & Rettig, 1995) and not accounting for the role of environmental or other triggering factors that may be involved in the onset of OCD (Abramowitz & Siqueland, 2013).

From a psychological perspective, behavioural models were an important forerunner to more contemporary conceptualisations of OCD, based on Mowrer's two-factor theory of fear and avoidance (Shafran, 2006). This behavioural model holds that obsessions and compulsions develop as a result of learning and classical conditioning, whereby obsessive thoughts become associated with anxiety, and compulsions are associated with relief (Shafran, 2006). However, behavioural models were limited by their inability to conceptualise symptoms and experiences that are unique to OCD, and disputed due to the fact that many OCD patients did not identify with the classical conditioning experiences posited by the model (Abramowitz & Siqueland, 2013). As a result of these limitations, behavioural theories were replaced by cognitive-behavioural approaches, which have become the dominant psychological school of thought in the conceptualisation of OCD. Although there are a range of cognitive-behavioural models, the common understanding shared by this paradigm is that it is the *meaning* (or the appraisal) that is placed on the intrusive thought, rather than the thought itself, that informs the cognitive process of amplifying the severity and recurrence of obsessions (Shafran, 2006). Different appraisals or dysfunctional beliefs are emphasised in different cognitive-behavioural models, i.e., inflated responsibility (Salkovskis & McGuire, 2003), thought control (Clark & Purdon, 1993), and exaggeration of threat (Frost & Steketee, 1997). Descriptions of the six primary cognitive appraisals central to OCD defined by the Obsessive Compulsive Cognitions Working Group (Frost & Steketee,

1997) are summarised in Table 2.1. below. In keeping with the heterogeneous nature of OCD, different patients may present with varying and/or overlapping cognitive appraisals.

Table 2.1: Cognitive appraisals central to OCD. Adapted from Abramowitz & Siqueland, 2013, p157.

Appraisal	Description
Inflated responsibility	Belief that one has the capacity to cause harm and/or is responsible for the prevention of harm (Salkovskis & McGuire, 2003).
Thought control	Dysfunctional beliefs about the importance of controlling obsessive thoughts, and fearing the consequences of not doing so (Clark & Purdon, 1993).
Over-importance of thoughts	Misinterpretations about the meaning of thoughts, i.e., that the mere presence of a thought is of moral consequence (Rheaume, Freeston, Dugas, Letarte, & Ladouceur, 1995).
Exaggeration of threat	Excessive beliefs about the threat of danger or disaster associated with obsessions (Frost & Steketee, 1997).
Intolerance of uncertainty	Difficulty with ambiguity, change, and unpredictability (Carr, 1974).
Perfectionism	A preoccupation with maintaining standards of perfection, and excessive concerns in relation to making mistakes (Frost & Steketee, 1997).

Although many of these appraisals (such as inflated responsibility) are useful in differentiating OCD from other mental disorders (Frost & Steketee, 1997), it can also be suggested that some appraisals are, to some extent, common in the general population (for

example, perfectionism). That being said, cognitive-behavioural models have made meaningful contributions to the field by effectively illuminating the central role of cognition in OCD.

In summary, there are two primary paradigms that propose different conceptualisations of the etiology of OCD: biological and psychological. The utility of the biological approach is that it highlights the fundamental role of brain structures and neurochemistry in OCD. It cannot be denied that certain structures of the brains of individuals with OCD function differently to those without the condition, which has been demonstrated by way of state-of-the-art technology involving neuroimaging (e.g. Wu et al., 2013). However, whether OCD occurs as a result of altered brain structures, or whether OCD alters brain chemistry, is still not clear (Schneider, 2019). Cognitive-behavioural models, on the other hand, have been helpful in illustrating the cognitive processes central to OCD, and – to some extent – in distinguishing OCD from other psychological conditions (such as anxiety disorders). Although neither paradigm presents a clear *cause* of OCD, both are useful in understanding the neuropsychiatric and cognitive components of this complex disorder. Further, both biological models of and cognitive-behavioural approaches to OCD have played a critical role in the development of evidence-based treatment interventions, in which a great deal of progress has been made in the last three decades. A brief discussion of first-line treatment interventions for OCD follows below.

2.1.3. Treatment. A large body of evidence endorses the effectiveness of both cognitive-behavioural therapy (CBT) and pharmacotherapy in relieving OCD symptoms (Lack, 2012). Research indicates that CBT holds the most promise for relieving OCD symptoms in adults (Abramowitz et al., 2018; Hirschtritt et al., 2017) with treatment focusing on correcting distorted cognitive appraisals, and terminating compulsive responses (Abramowitz & Siqueland, 2013). A method of CBT named exposure-response prevention

(ERP) has generated the most empirical support in relieving OCD symptoms (Hirschtritt et al., 2017). This involves repeated confrontations with stimuli that trigger obsessions (exposure) while the patient withholds from performing compulsions (response prevention) with the support of a therapist (Abramowitz et al., 2018). Exposures are carefully designed and re-created within the therapeutic space as well as in homework exercises, involving both imaginary and situational exposures, and requiring a close and cooperative relationship between the therapist and patient (Lack, 2012). Exposures cause an initial increase in obsessional anxiety, which eventually recede with time in a process named “habituation”, i.e., reducing the instinctive response to a stimulus by way of repetition (Abramowitz & Siqueland, 2013, p.156). Response prevention – involving the suppression of compulsions – is a method of reframing the cognitive mechanisms that are used to avoid and manage obsessional anxiety, and helps to internalise and solidify the process of habituation (Abramowitz & Siqueland, 2013). ERP methods have shown to be successful in significantly reducing OCD symptoms across multiple clinical trials, with large effect sizes ranging from 1.16 – 1.72, and approximately 60% of OCD patients experiencing a reduction in symptoms following treatment (Lack, 2012). When CBT with ERP is facilitated by an experienced clinician, it may be the most effective form of treatment for mild to moderate cases of OCD in adults (Hirschtritt et al., 2017). Despite this, it is not uncommon for some residual symptoms to remain following ERP (Abramowitz & Siqueland, 2013).

Pharmacological treatment is often used together with CBT, particularly for severe cases of OCD with poor insight (Franklin & Foa, 2011). Clomipramine, a tricyclic antidepressant, was the first medication documented to be successful in treating OCD and is still regarded as reliable and effective (Hirschtritt et al., 2017). In addition, monotherapy with the selective serotonin reuptake inhibitors (SSRIs) – namely fluoxetine, sertraline, fluvoxamine, citalopram, escitalopram and paroxetine – have demonstrated effectiveness in

reducing OCD symptoms across a large number of published control trials and clinical guidelines (Franklin & Foa, 2011; Hirschtritt et al., 2017; Kellner, 2010; Stein, 2019).

Although SSRIs are better tolerated and associated with fewer adverse effects than clomipramine, there is not clear evidence to determine whether clomipramine or SSRIs are more effective (Hirschtritt et al., 2017). Thus, all of these agents are considered first-line interventions in the pharmacological treatment of OCD (Kellner, 2010). Higher doses of SSRIs are recommended for more effective results, for example, up to 80mg of fluoxetine and 40 mg of escitalopram (Pittenger, & Bloch, 2014) over a trial period of 12 weeks (NICE, 2005).

For individuals who do not respond to clomipramine or the SSRIs, augmentation with antipsychotic agents has shown to be an effective second-line treatment option (Kellner, 2010). In this way, both CBT (particularly with ERP) and pharmacotherapy have shown to be effective interventions in the treatment of OCD, either independently or in combination (Hirschtritt et al., 2017). These evidence-based interventions for OCD fall into the category of formal help.

2.2. Help-seeking and mental health

Henshaw and Freedman-Doan (2009) illuminate the importance of help-seeking for mental health problems in the following way: “The process of change in psychotherapy, regardless of the clinician’s orientation, length of treatment, or outcome measure, begins with this: the client must attend a first session” (p.420). Unfortunately, people’s resistance and reluctance to seek professional help for psychological distress is one of the most widely documented obstacles to delivering mental health services (Clement et al., 2015), and is a core contributor to the large global mental health treatment gap, describing the gap between those requiring mental health services and those receiving it (WHO, 2008). Further, the problem of untreated

mental illness has shown to be larger and more problematic in developing countries, such as South Africa (WHO, 2008).

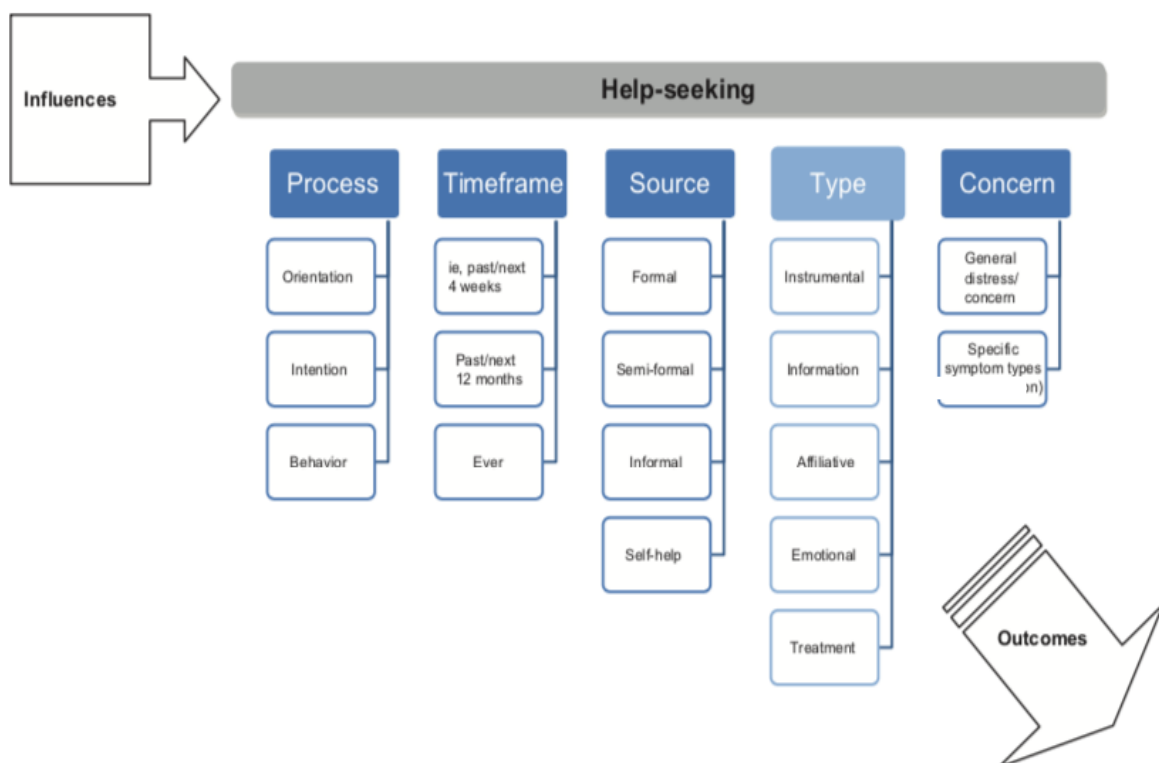
Research indicates that there are many reasons as to why individuals with mental illness do – or do not – seek help, and these reasons tend to vary according to the condition and context. Indeed, these reasons may exist not only within the individual, but also on a systemic level, with stigma emerging as a particularly important systemic barrier to help-seeking across mental health studies (Picco et al., 2018). Summarising the findings of studies focusing on help-seeking across the spectrum of all mental disorders is beyond the scope of this thesis. However, it is important to note that mental disorders present in heterogeneous ways. In turn, illness-factors and symptomology – for example, the content and nature of obsessions in OCD – may play a significant role in the use of mental healthcare services (Besiroglu & Agargun, 2006). Further, the condition itself is just one variable that exists within a complex combination of factors, and it is the interplay of these factors that ultimately determines whether or not an individual seeks help. A definition of help-seeking should illuminate the complexity of the help-seeking process, and clarify how the concept is approached in the current study.

2.3. The help-seeking process: a conceptual discussion

The notion of help-seeking for health problems first emerged in medical literature in the 1950s and involved exploring “illness behaviour”, which describes the way patients manage and remedy their physical health symptoms – including the process of seeking and utilising health services (Sirri, Fava & Sonino, 2013, p74). Since then, the concept of help-seeking has evolved and has been investigated beyond the realm of physical health, receiving particular attention in the context of mental health in recent times (Picco et al., 2018). However, despite an increase in attention, there seems to be some inconsistency in the mental health literature

regarding the meaning of help-seeking as a concept. It appears that this lack of clarity is partly due to the broad and complex nature of help-seeking (Rickwood & Thomas, 2012), as well as differing definitions emerging in the literature. That being said, there exists some consensus across definitions about help-seeking being an *adaptive process*, which begins with the identification or recognition of a *problem*, and involves *efforts* to solve or improve the problem by way of external assistance (Cornally & McCarthy, 2011; Picco et al., 2018; Rickwood & Thomas, 2012; Waltz, Stickland & Lenz, 2016). Further, help-seeking as a process involves various different domains and manifestations. Rickwood & Thomas (2012) effectively illuminate the different dimensions of help-seeking for mental health problems in Figure 2.1 below:

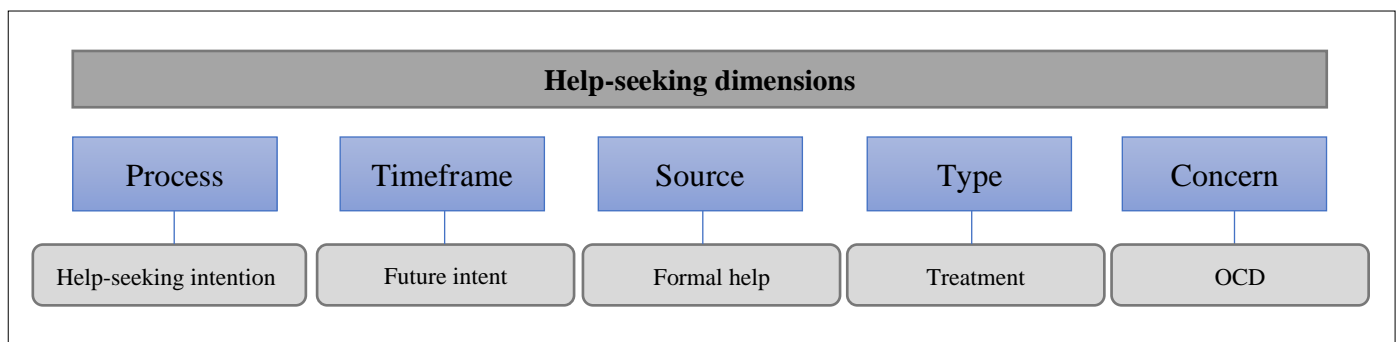
Figure 2.1. Help-seeking for mental health problems (Rickwood & Thomas, 2012, p.181)



These dimensions include the form or “process” of help-seeking (i.e., intention or behaviour), the “time frame” that is being studied (future or past), the “source” and “type” of assistance being sought (i.e., formal or informal), as well as the “concern” or mental health problem at hand (Rickwood & Thomas, 2012, p.181). Furthermore, this framework accounts for the various influences that impact help-seeking, i.e., barriers to care, as well as the different outcomes that can occur as a result of help-seeking, such as treatment behaviours.

Based on this discussion, help-seeking can be understood as a dynamic, multi-dimensional process which can manifest in different ways, i.e., behaviourally (via action) or cognitively (via intention). Considering the multi-faceted nature of this concept, it is therefore necessary to clearly outline the dimensions of help-seeking that are of interest when conducting help-seeking research. Accordingly, the dimensions of help-seeking that are of interest in this study are summarised in Figure 2.2 below.

Figure 2.2. Help-seeking dimensions in the current study



2.4. The OCD help-seeking dilemma

Despite the existence of evidence-based treatment and formal sources of help for OCD, the majority of cases remain underdiagnosed and untreated (Stein et al., 2019). A review of current OCD treatment data suggests that fewer than 10% of cases that come to clinical attention receive evidence-based treatment (Hirschtritt et al., 2017). In keeping with general

mental health trends, failure to initiate treatment or seek help for symptoms is a fundamental problem for individuals with OCD (Cludius et al., 2015; Garcia-Soriano et al., 2014; Marques et al., 2010). Furthermore, research shows that OCD patients are less likely to seek help compared to those diagnosed with other mental disorders, including panic disorder and depression (Belloch et al., 2008). According to a WHO bulletin, the treatment gap for OCD is larger than for schizophrenia, depression, and bipolar disorder (Kohn, Saxena, Levay, & Saraceno, 2004). Research has also highlighted an added complexity, in that individuals who do seek assistance for OCD typically delay the process of help-seeking for many years. The most commonly reported delay time in the literature is approximately eight years (Abramowitz et al., 2018; Belloch et al., 2008; Hirschtritt et al., 2017), although many studies observe longer delays. For example, Garcia-Soriano et al. (2014) describe a delay time of between 10 to 17 years across a review of studies published in the United States of America (USA). The lengthy duration of untreated illness (DUI) associated with OCD is problematic, since early diagnosis and intervention have shown to have a significant impact on the trajectory and prognosis of the condition (Albert et al., 2019). Therefore, it is essential to investigate the OCD help-seeking dilemma and to understand the factors that influence it, in order to improve treatment outcomes. The problem of help-seeking for OCD has been highlighted and explored in a number of international studies, and these findings are discussed below.

2.5. Predictors of help-seeking

2.5.1. Severity. It can to some extent be expected that symptom severity would be associated with the intention to seek help for OCD, based on the assumption that those in greater distress would be more inclined to seek relief from their symptoms. This has been illustrated in a number of studies, including that of Besiroglu et al. (2004) reporting that

higher scores on the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) – the gold-standard measure of OCD symptom severity – correlated positively with help-seeking behaviour. Correspondingly, Ruscio et al. (2010) found that the majority (93%) of patients who received treatment in the previous 12 months had severe OCD at baseline. A similar finding was reported by Cullen et al. (2008) as well as Mayerovitch et al. (2003), demonstrating a significant positive relationship between OCD symptoms and treatment utilisation. Thus, it can be inferred that patients with more severe symptoms are more likely to seek help than others with milder, less impairing symptoms.

2.5.2 Beliefs about illness and treatment. The majority of studies indicate that individuals with knowledge about, or insight into their OCD and positive beliefs about treatment are more likely to seek formal help. For example, Belloch et al. (2008) found that individuals with OCD are more likely to seek professional help if they have prior information regarding the effectiveness of mental health services. Accordingly, Robinson and Salkovskis (2017) found that exposure to accurate information about OCD and having confidence in health practitioners are two key facilitators of help-seeking behaviour. In the same vein, having insight into the irrationality and excessiveness of symptoms has emerged as an important predictor of help-seeking intention and behaviour for OCD (Besiroglu & Agarun, 2006; Belloch et al., 2008; Demet et al., 2010). Further, Besiroglu and Agarun (2006) also found that the degree of insight correlated with Y-BOCS scores, and they suggest that these two factors together mobilise help-seeking, because “the ability to recognize that a problem exists prompts distress or motivates the decision to seek health care” (Besiroglu & Agarun, 2006, p.106). Similarly, Belloch et al. (2008) found that OCD patients who sought professional help early were more likely to have insight into the level of interference caused by their OCD symptoms. Thus, these studies demonstrate that illness-related beliefs, and

beliefs about treatment play an important role in facilitating help-seeking intention and behaviour for OCD.

2.6. Barriers to help-seeking

In addition to predictors, a large body of research has focused on barriers to help-seeking for OCD. The themes that have emerged involve attitudinal or psychological variables including stigma and shame, secrecy and mental health literacy, as well as structural factors.

2.6.1. Stigma and shame. Stigma has been defined by the WHO as “a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society” (WHO, 2001, p.16). The stigma that is associated with a mental disorder has been widely documented, and creates a double burden for those diagnosed (Rüsch, Angermeyer, & Corrigan, 2005). It has been suggested in the literature the stigma encompassing mental illness is often “worse than the condition itself” (Carr & Ashby, 2020, p.1). Thus, it is somewhat unsurprising that fear of being stigmatised has emerged as one of the primary reasons that individuals delay or fail to seek help for OCD (Belloch et al., 2008; Besiroglu, et al., 2004; Robinson, Rose, & Salkovskis, 2017; Williams et al., 2012). Furthermore, as implied by the WHO definition, stigma induces painful feelings of shame and distress as a result of *otherness* and social exclusion. A large body of literature spotlights the role of shame in delaying help-seeking processes for OCD. For example, Marques et al. (2010) found that more than half (53.7%) of participants in a USA-based sample indicated that they felt ashamed of their OCD, and that this prevented them from seeking treatment. Similarly, Williams et al. (2012) highlighted that concerns about stigma and shame were experienced as “particularly distressing” and a barrier to the help-seeking process among African Americans (p.7). Glazier et al. (2015) found an even higher endorsement of shame barriers among OCD patients, with 75% of participants

(n=164) endorsing “feeling ashamed of my problems” as a treatment barrier (p.3). This finding was reinforced by a qualitative study (Robinson et al., 2017) in which 75% of respondents reported that shame was a barrier to seeking professional help for their OCD. These studies demonstrate the fundamental role of stigma and shame in the experience of OCD, and ultimately in preventing individuals from reaching out for help.

2.6.2. Secrecy. Stigma has many powerful ripple effects, including the problem of secrecy – whereby individuals with OCD conceal their symptoms to avoid being stigmatised, and at the cost of seeking help. Indeed, it seems that secrecy is a hallmark feature of OCD, which has been termed “the secret illness” (Robinson et al., 2017, p.7). Many studies highlight the performative efforts undertaken by individuals to hide their OCD from friends, family, partners, children, colleagues, and even doctors and therapists (Belloch et al., 2008; Glazier, Wetterneck, Singh, & Williams, 2015; Robinson et al., 2017). There are a number of factors, in addition to stigma-related fears, that have emerged in the literature to explain the secrecy associated with OCD. For example, it has been noted that OCD symptoms by nature – and obsessions in particular – are generally *private experiences*, making them easy to conceal (Abramowitz et al., 2018; Hirschtritt, 2017). It has also been observed that feelings of guilt about the nature of obsessions, and fear that the content of obsessions might be held against the individual, are meaningful reasons for the concealment of symptoms (Belloch et al., 2008). These factors fuel secrecy and contribute to the OCD help-seeking dilemma.

2.6.3. Poor mental health literacy. Mental health literacy is defined as “knowledge and beliefs about mental disorders which aid in their recognition, management or prevention” (Furnham & Swami, 2018, p.1). This involves identifying and understanding mental health symptoms, and knowing what to do and where to go for help (Furnham & Swami, 2018). A number of studies have investigated mental health literacy concerning OCD and have shown that the condition is poorly understood by the general public (Stewart, Grunthal, Collins, &

Coles, 2019). For example, a study involving a community sample revealed that only 33% of participants were able to identify OCD symptoms in a vignette (Coles, Heimberg, & Weiss, 2013). Rather than being understood as a disabling mental disorder, OCD is often perceived as quirky “oddball habits” or strict behaviours involving cleanliness (Fennell & Liberato, 2007, p.317). This is largely due to inaccurate portrayals of OCD in the media, which typically trivialises OCD or depicts the condition in a comedic way (Pavelko & Myrick, 2015). OCD is also commonly mistaken as being part of a person’s *personality* (Stewart et al., 2019). As such, OCD is often confused with obsessive-compulsive personality disorder (OCPD), which is defined in the DSM-5 as “a pattern of preoccupation with orderliness, perfectionism, and control” (American Psychological Association, 2013, p.645). Indeed, individuals with OCD may embody certain personality traits – such as perfectionism – that are shared with OCPD features. Further, individuals with obsessions and compulsions concerning symmetry and hygiene may present in a similar way to personality structures characterised by orderliness and control, and therefore the misunderstandings surrounding OCD and OCPD are to some extent understandable. However, the misperceptions associated with OCD in the public domain are problematic, and contribute to individuals with OCD often being ill-equipped to recognise the nature of their symptoms (Stewart et al., 2019). Further, failure to recognise symptoms, or lack of illness insight, has been highlighted as one of the key barriers to help-seeking among OCD patients (Garcia-Soriano et al., 2014). An author with a personal experience of OCD illuminates how this can happen in the following way:

Before my diagnosis, I had heard of OCD; it was something that people would sometimes joke about ... someone diagnosed with OCD was just a type of person who liked to have their things tidy. Unknown to me was how OCD could in fact stop one’s

functioning, take away one's life as one had known it previously (Brooks, 2011, p.252).

The detrimental impact of poor mental health literacy on OCD treatment is supported by a large body of literature. For example, Belloch et al. (2008) found that nearly half of participants with OCD (46.2%) were not able to recognise their symptoms, and that only one patient consulted with a professional due to being equipped with prior information about the disorder. Similarly, Poyraz et al. (2015) reported that 60.4% of OCD patients delayed seeking help because they did not believe that their OCD symptoms were linked to a psychiatric condition. Mavrogiorgou, Sibers, Kienast, and Juckel (2015) discovered that the most common reason for treatment delays was that “the patient was not convinced of having a mental illness such as OCD and of the necessity for treatment” (p.1130). These studies underscore the problem of poor mental health literacy and general misunderstandings in relation to OCD, and exemplify how this problem hinders the help-seeking process.

2.6.4. Structural factors. The final category of help-seeking barriers which have emerged in the literature can be grouped under structural factors, i.e., issues that originate due to system-level influences, including finances, lack of medical aid or insurance, and logistics such as transport and time (Marques et al., 2010, Poyraz et al., 2015; Williams et al., 2012). The most frequently reported barrier in this category includes the financial burden of mental health services, with OCD patients commonly reporting that concerns about cost and health insurance curb service use. For example, Glazier et al. (2015) found that more than half (53.7%) of OCD patients agreed that being “worried about cost” would prevent them from seeking help (p.3), and 39% of the sample indicated that issues relating to medical insurance would be a barrier to care. Similarly, in a study conducted by Marques et al. (2010), 57.1% of the sample endorsed “I was worried about how much it would cost” as a treatment barrier, and 37.8% indicated that “health insurance would not cover treatment” was an obstacle to

service utilisation (p.473). A related finding was demonstrated by Williams et al. (2012), who found that cost of treatment was one of the most commonly endorsed barriers to formal care, and highlighted that uninsured patients were most likely to be concerned about finances. In addition, both Marques et al. (2010) and Glazier et al. (2015) found that logistical factors – including time in treatment and transport – were significant obstacles to service use.

2.7. Help-seeking for OCD: Additional factors

Additional factors associated with help-seeking for OCD that have emerged as themes in the literature include (a) comorbidity, (b) the content of obsessions, and (c) socio-demographic factors. Findings have been mixed, however. For example, concerning comorbidity, there are studies indicating that OCD patients who seek formal help are likely to have comorbid disorders (Cullen et al., 2008; Torres et al., 2006), whereas others found no correlation between comorbidity and help-seeking (Besiroglu et al., 2004; Demet et al., 2010; Goodwin et al., 2002). Interestingly, Cullen et al. (2008) highlighted that individuals demonstrating personality traits commonly found in OCPD, such as perfectionism and a need for control, are less likely to seek help and receive treatment. However, this finding has not been verified in other studies. With regard to the content of obsessions, one study found that individuals who experience obsessions centred on “taboos” of an immoral or destructive nature (such as violence) are more likely to seek help, due to the distressing nature of their symptoms (Garcia-Soriano et al., 2014). In apparent contrast, there are other studies reporting that OCD patients with blasphemous or violent obsessions may find it harder to disclose and seek help (Glazier et al., 2015). Studies have also produced mixed results regarding socio-demographic characteristics, with some suggesting that factors such as age, ethnicity, and marital status influence help-seeking (Subramaniam, Soh, Vaingankar, Picco, & Chong, 2013), while others found no relationship (Besiroglu & Agarun, 2006). Age in particular appears to play a role in

help-seeking for OCD, as studies have highlighted that patients below the age of 60 are generally more inclined to seek help (Cullen et al., 2008). This is possibly as a reflection of improved awareness about mental health and greater acceptance surrounding help-seeking within the younger generation, compared to older communities.

In summary, it is evident that a wide range of factors influence the formal help-seeking process among people with OCD. While some common barrier and predictor themes have emerged, there are also inconsistencies across studies. It is important to note that these studies were conducted in international settings, and generally within resource-rich locations such as the USA (e.g., Glazier et al., 2015; Marques et al., 2010; Torres et al., 2006; Williams et al., 2012). A systematic review of global literature focusing on help-seeking patterns for common mental disorders (including OCD) has confirmed this reasoning, highlighting that the majority of research focusing on this topic has been conducted within high income countries (Roberts et al., 2018). International findings should be interpreted and applied to the local context with caution, due to marked discrepancies between health systems.

2.8. Mental health help-seeking in South Africa

2.8.1. Predictors and barriers. A body of literature has explored patterns of help-seeking for mental health concerns and service-use in South Africa, with studies mostly focusing on problems such as substance use, sexual assault and abuse, and maternal mental health in particular (e.g., Field, Abrahams, & Honikman, 2020; Myers, Louw, & Fakier, 2008; Smith, Bryant-Davis, Tillman, & Marks, 2010). The majority of these studies have explored *barriers* to help-seeking within this setting, with focus on structural and system-level barriers being prominent. For example, research conducted by Smith et al. (2010) highlights that socio-cultural, economic, and structural factors are significant barriers to help-seeking behaviour for survivors of abuse in this setting. Such factors include economic

obstacles and a lack of education, contributing to poor mental health literacy and resulting in individuals being misinformed and ill-equipped to seek out appropriate sources of help for psychological and sexual abuse (Smith et al., 2010). Barriers within the public mental health service system are also highlighted, involving clinics that are under-resourced and short-staffed, with delayed treatment times (Smith et al., 2010). In the same vein, Field et al. (2020) found that problems of physical access and transport, a lack of knowledge about sources of help, as well as concerns about confidentiality and stigma were barriers to mental health help-seeking among a group of adolescent mothers in South Africa. Similarly, a study conducted by Myers et al. (2008) suggests that poor mental health literacy, long waiting-lists and delays, and financial obstacles are significant barriers to help-seeking among individuals with substance use disorders in the Western Cape region.

Some studies have also observed predictors or enablers of mental health help-seeking in South African settings. For example, Myers et al. (2008) demonstrated that financial resources were positively correlated with help-seeking among South African individuals with substance-use problems. Social support was another enabler of help-seeking for mental health problems in South African settings (Myers et al., 2008; Field et al., 2020). Socio-demographic factors such as race and gender were also found to be associated with mental health service utilisation among a group of first year university students (Bantjes et al., 2020).

These studies highlight the role of environmental, system-level factors in patterns of mental health service and help-seeking in South Africa. That being said, it is also important to note that these studies explore a range of different mental health concerns, and so commonalities among these studies should be considered with the diversity of issues in mind. It is plausible that barriers impeding help-seeking for abuse, for example, may differ from

OCD-related barriers, even within the same setting. An exploration of South African literature focusing on help-seeking for OCD specifically follows below.

2.8.2. *Help-seeking for OCD in South Africa.* Although some OCD research has been conducted in South Africa (e.g. Hoppe, 2009; Kohler et al., 2018; Malemela & Mashegoane, 2019; Stein, 1996), to my knowledge none of these studies have investigated the topic of help-seeking intention for OCD in this setting. Notably, there is one recent study that investigated experiences of quality of life among South African adults with OCD, with a strong focus on local perceptions and experience, although the study did not focus on the topic of help-seeking and service-use specifically. The authors briefly highlight how local treatment challenges – described as “limited specialisation, affordability, and accessibility” – are likely to impact quality of life for OCD patients, and call attention to the need for further research in this domain (Kohler et al., 2018, p.9).

The absence of literature focusing on help-seeking and treatment for OCD in South Africa is problematic, considering the significant mental health service-use challenges that exist in this setting as indicated in the studies reviewed above (e.g., Field et al., 2020; Myers et al., 2008; Smith et al., 2010). Similar to other developing nations, mental health services are significantly under-funded in South Africa (Docrat et al., 2019). Moreover, the South African healthcare system is defined by many context-specific difficulties. One such challenge includes the dual-sector nature of the healthcare system, consisting of a large public sector that serves the bulk (approximately 84%) of the South African population, and a small private sector that caters to the more prosperous minority (Docrat et al., 2019). In contrast to some other BRICS countries, the majority of the population in South Africa is uninsured (Romaniuk, Poznanska, Brukało, & Holecki, 2020), and recent research has revealed that less than 1% of the country’s uninsured population requiring mental healthcare in South Africa is

receiving public inpatient treatment (Docrat et al., 2019). Furthermore, South Africa is challenged by unique structures of inequality with significant disparities in urban and rural mental health resources (Jack et al., 2014), along with problems of unemployment, poverty, and a culture of violence, among other systemic stressors that exacerbate mental health problems (Burns, 2011). Importantly, the country faces a complex burden of disease, with comorbidities between psychiatric disorders and other chronic health conditions, such as HIV, tuberculosis, diabetes mellitus, and malaria (Romaniuk et al., 2020). These system-level challenges impact individuals seeking help for mental health services, and contribute to concerns about fragmented service delivery, transport, and affordability, as highlighted by Field et al. (2020), Myers et al. (2008), and Smith et al. (2010).

To summarise, while there is data on mental health help-seeking in South Africa, there is a dearth of research focusing on help-seeking for OCD specifically. Barriers and predictors relating to help-seeking for OCD are expected to be specific to this context, due to the convoluted nature of mental health service delivery in this setting.

2.9. Conclusion

This chapter offers a critical discussion of the conceptualisation of OCD, to demonstrate the complexity of the psychopathology and to introduce the reader to relevant theoretical concepts and tensions. In addition, I have reviewed relevant help-seeking literature to clarify its conceptual definition, and to illustrate the multifaceted nature of the OCD help-seeking dilemma. I have drawn on studies that describe the various factors that influence the help-seeking process, both in terms of facilitators and barriers to formal service use. Although several common themes have been identified within the literature, there are also mixed results, and it is important to note that the majority of studies have investigated the problem

of seeking help for OCD within well-resourced nations, and there exists a marked absence of research on the topic in South Africa.

Chapter 3: Theoretical Framework

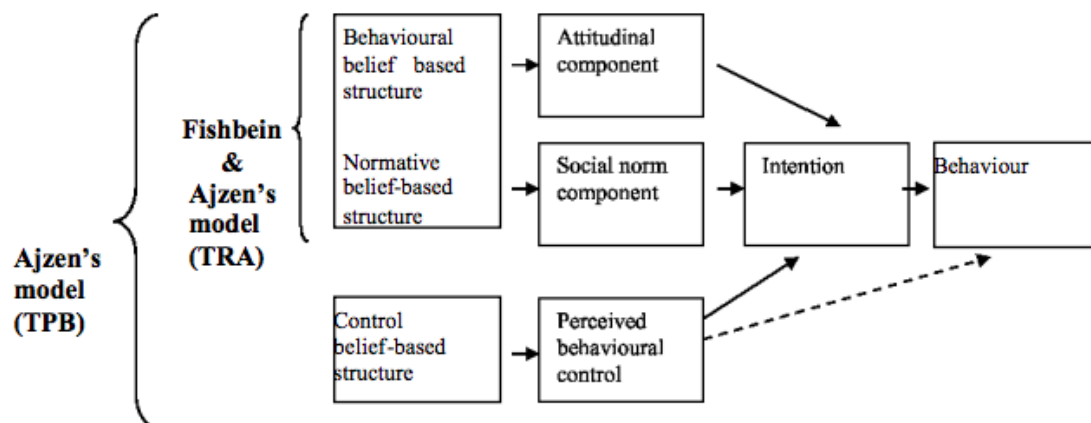
A theoretical framework is a fundamental part of the thesis inquiry, and is defined by Eisenhart as “a structure that guides research by relying on a formal theory ... constructed by using an established, coherent explanation of certain phenomena and relationships” (1991, p.5). The theoretical framework that informed this study is the health belief model (HBM; Rosenstock, 1974, 1990), which is one of the most established and influential theories for explaining and predicting healthcare utilisation. The HBM guided the conceptualisation, structure, and planning of this study, as well as the analytical approach following data collection. This chapter begins with an overview of other theoretical models of help-seeking for help-seeking intention, which is followed by a conceptual overview of the HBM specifically, a discussion of its application to mental health, and an outline of the way that the current study has utilised the HBM.

3.1. Theoretical models of help-seeking

In addition to the HBM, a number of other psychological theoretical models to explain help-seeking intention were explored in the current study. To contextualise the preference for, and decision to use the HBM to guide the assessments and analyses here, a brief overview of the most relevant competing models will be discussed in this section. These are the Theory of Reasoned Action (TRA; Ajzen & Fishbein, 1980) and the Theory of Planned Behaviour (TPB; Azjen, 1991) specifically. There exists some conceptual overlap across the TRA, TPB, and the HBM, which generally draw on social learning theory (i.e., Bandura, 1977a) and focus on cognitive-behavioural processes (Henshaw & Freedman-Doan, 2009).

The TRA (Ajzen & Fishbein, 1980) proposes that two key constructs influence intention and behaviour: attitudes and subjective norms. Specifically, the model hypothesises that individuals will be motivated to engage in certain behaviours based on the extent to which they perceive the behaviour in a positive way (attitude) and whether their significant others endorse the behaviour (subjective norms) (Andrew-Smith & Biddle, 1999). The TRA was expanded into the TPB (Ajzen, 1991) which introduced the construct of control beliefs, namely the concept of “behavioural control”, describing the extent to which an individual believes in their capacity to execute a particular behaviour (Taylor et al., 2007 p.7). Both the TRA and TPB posit that the best predictor of behavioural action is intention, and thus focus on the attitudes, norms, and personal control beliefs that influence intention and subsequently, behaviour (Montano & Kasprzyk, 2015). A diagram illustrating the TRA and TPB is presented below.

Figure 3.1. The TRA and the TPB (Taylor et al., 2007 p.7).



Research has shown that the TRA and the TPB have been useful in explaining a range of health-related behaviours, including preventative behaviours, substance use, cancer screening, and general healthcare utilisation (Andrew-Smith & Biddle, 1999; Montano & Kasprzyk, 2015; Taylor et al., 2007). In the context of the current study, these models have

been useful to consider and draw from, particularly regarding the focus on intention as a key predictor of health behaviour. However, an important critique of the TRA and TPB is that these models are biased towards *individual* cognitive and behavioural processes, largely ignoring contextual barriers and variables which may be equally important in influencing help-seeking and service use (Taylor et al., 2007). Given that one of the aims of the current study is to investigate OCD help-seeking *barriers* – which may be internal or external – the TRA and the TPB were thus deemed less relevant to the research objectives compared to the HBM, which manages to overcome this limitation to some extent. This model and its relevance to the research of aims of the current study is described next.

3.2. The HBM

The HBM emerged in the early 1950s, first developed by psychologists wanting to understand the reasons why individuals failed to engage with illness-preventative programmes, and later refined to explain the way individuals react to their symptoms and utilise health services once diagnosed (Champion & Skinner, 2008). As such, the HBM has been used as a basis for explaining the way people manage and treat their health symptoms, and has served as a guide for informing many public health interventions (Champion & Skinner, 2008). The HBM is based on the hypothesis that service utilisation is influenced by a number of key constructs, or health beliefs, namely: illness susceptibility and severity, treatment benefits and barriers, self-efficacy, and various moderating variables (Kim & Zane, 2016). Such moderating variables include socio-demographic factors, as well as cues to action, which are environmental triggers that mobilise health behaviours (Henshaw & Freedman-Doan, 2009). Specifically, the HBM holds that individuals are motivated to engage with health services based on the extent to which they believe they are susceptible to a condition, that the effects of the condition are severe, that there are many benefits and few

barriers to treatment, and that they possess a sense of personal self-efficacy required to improve with intervention (Stretcher & Rosenstock, 1997). The concept of self-efficacy refers to an individual's belief in their ability to effectively perform a task or achieve a goal (Bandura, 1977b) and is similar to the construct of behavioural control as posited by the TPB. In addition, the HBM holds that health beliefs are influenced by certain variables, namely socio-demographic factors, and more recently, cues to action (Champion & Skinner, 2008). Furthermore, these health beliefs are grouped according to *threat factors* (susceptibility and severity) and *expectation factors* (benefits, barriers, and self-efficacy), and the model suggests that it is the combination and interaction of threat and expectation factors that inform engagement with formal health services (Stretcher & Rosenstock, 1997). To clarify the model further, definitions of key HBM health beliefs are summarised in Table 3.1 below.

Table 3.1. Key constructs of the traditional HBM. Adapted from Champion & Skinner (2008).

Construct		Definition
Threat Factors	Susceptibility	Beliefs about the likelihood of contracting an illness, or the acknowledgment of being vulnerable to the negative consequences of a condition.
	Severity	Beliefs about the level of distress and danger associated with symptoms, or the potential for a condition to have a destructive impact – physically, socially, vocationally, or otherwise.
Expectation Factors	Perceived treatment benefits	Perceived rewards associated with healthcare services, and the perception that treatment would be effective in alleviating symptoms and reducing the threat of illness.
	Treatment barriers	Expectations about the potential negative effects of engaging in healthcare services, due to obstacles that may impede the process of engaging with healthcare services.
	Self-efficacy	Beliefs about one's capacity to change through engaging with healthcare services, and effectively carry out treatment outcomes.

3.3. Critique of the HBM

The HBM has both strengths and shortcomings. A key advantage of the HBM is the large body of evidence that exists in support of the model, which has been successfully replicated a multitude of times across a wide range of studies, including some on psychiatric disorders (Janz & Becker, 1984). Skinner, Tiro, and Champion (2015) summarised systematic reviews of the model's performance across 89 studies, demonstrating significant empirical support for HBM constructs, particularly perceived benefits and barriers. A second strength includes its simplicity, which offers a clear and comprehensive framework that effectively unravels the complexity of health-related behaviour (Henshaw & Freedman-Doan, 2009). The intuitive nature of the model makes it easy to understand, put into practice, and test (Orji, Vassileva, & Mandryk, 2012). Further, although the model focuses on individual beliefs, it also accounts for contextual and social factors that may inform processes of service utilisation (Green, Murphy, & Gryboski, 2020), in contrast to the TPB and the TRA.

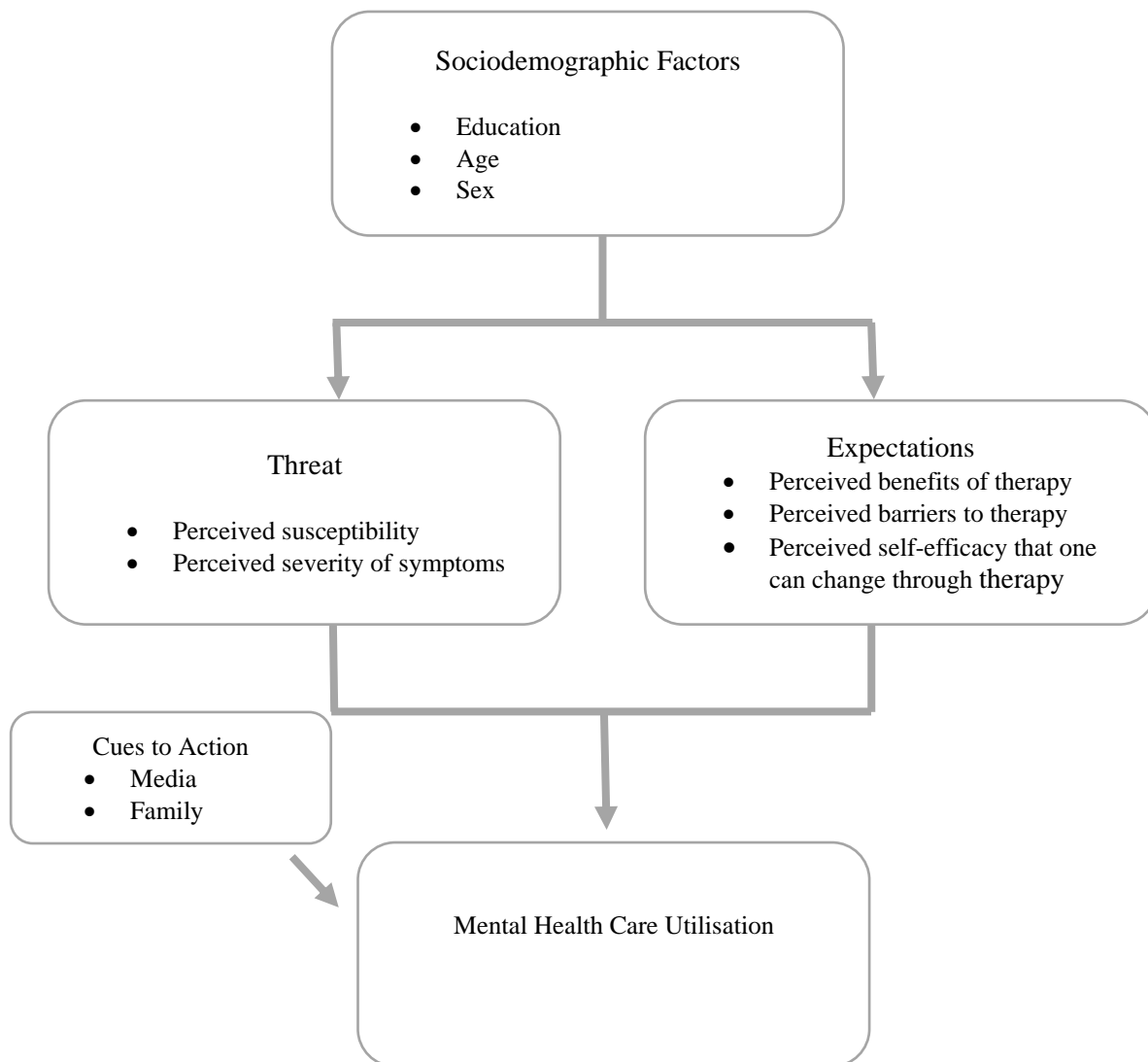
The HBM has however also received some criticism over the years. It has been suggested that, while the HBM is useful in understanding the process of initiating treatment, it may be restricted in its capacity to predict more longitudinal health-related outcomes (Henshaw & Freedman-Doan, 2009). Some authors have questioned the value of the *threat* component of the model, particularly the severity construct, due to its weak predictive power in some studies (Carpenter, 2010; Skinner et al., 2015). An additional shortcoming is that the model does not specify relationships between constructs, creating a lack of clarity and guidance regarding the interaction effects between variables (Orji et al., 2012). This has led to variability relating to the way the model has been applied over the years (Skinner et al., 2015). Notably however, it has also been highlighted that this may also be viewed as an advantage, as it offers adaptability for the model to be applied across a range of settings and health outcomes (Orji et al., 2012).

In this way, I have critically considered the usefulness of the HBM in the conceptualisation of this study, against the backdrop of other similar models (namely the TRA and the TPB). Despite its few shortcomings, the strengths of the HBM lend itself to the research aims of the current study – given that it is intuitive, empirically sound, appropriate for understanding treatment initiation (i.e. formal help-seeking), and sensitive to both the individual and contextual factors that influence service use.

3.4. The mental HBM

Although the HBM has traditionally been used to explain physical health behaviour, Henshaw and Freedman-Doan (2009) make a strong argument for the usefulness of HBM constructs in conceptualising and predicting the utilisation of mental health services. The authors highlight the value in the model's dyadic focus on benefits and barriers, which effectively captures the "cost-benefit analysis" involved in decision making (p.423). Further, the authors emphasise the clinical utility of the model, in that it accounts for both a) psychological perceptions and beliefs relating to healthcare utilisation, and b) system-level barriers, which are tangible components that can be identified and targeted in order to mobilise change (Henshaw & Freedman-Doan, 2009). Figure 3.2. below illustrates the HBM model in the context of mental health, as conceptualised by Henshaw and Freedman-Doan (2009). This adapted model has been recommended by other authors (Smith, 2009) as a valuable innovation when it comes to understanding and addressing the problem of underutilisation of mental health services.

Figure 3.1. Adapted HBM for mental health (Henshaw & Freedman-Doan, 2009, p.424).



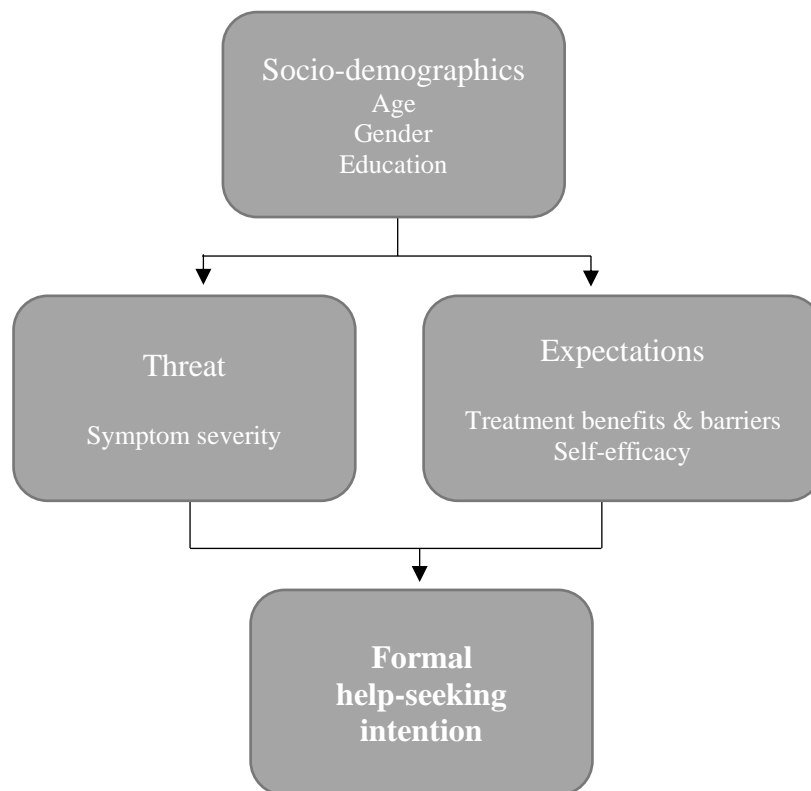
The utility of the HBM for mental health is supported by a growing body of research that has applied the HBM to mental health contexts to understand patterns of service utilisation, and which has yielded significant and meaningful results (Langley, Wootton, & Grieve, 2017; Nobiling & Maykrantz, 2017; O'Connor, Weeks, & Ong, 2014). Perceived benefits and barriers have emerged as particularly salient HBM constructs in the mental health literature, with the majority of studies finding either one or both of these constructs to be relevant to mental healthcare utilisation, and different dimensions of help-seeking. For example, Langley et al., (2017) found that perceived treatment benefits was the strongest predictor of help-

seeking intention among a sample of adults with generalised anxiety disorder. Similarly, O'Connor et al., (2014) found that both perceived benefits and barriers were direct predictors of help-seeking behaviour among a community sample of adolescents experiencing general psychological distress, although perceived benefits emerged as more significant predictors in their study. Kim and Zane (2016) demonstrated that perceived treatment benefits partially accounted for variation in help-seeking intention among students in psychological distress. Nobling and Maykrantz (2017) utilised the HBM to understand attitudes to mental health service utilisation among university students in a mixed-methods study, and found that treatment barriers (such as socio-cultural concerns and system-level challenges) emerged as key barriers to service use. Thus, it can be suggested that HBM constructs, and perceived treatment benefits and barriers in particular, are useful in explaining and predicting various forms of help-seeking, including help-seeking intention and behaviour.

3.5. The application of the HBM in this study

This study has drawn on the HBM to inform a working hypothesis about the primary factors that influence help-seeking intention among adults with OCD, namely socio-demographic variables, symptom severity, perceived treatment benefits, treatment barriers, and self-efficacy. Two HBM constructs were deemed not relevant to the current study, namely (a) perceived susceptibility, given that participants in the current had already received a diagnosis of lifetime OCD, and (b) cues to action, given that help-seeking *intention* is the studied health outcome, rather than behaviour or action. Further, it emerged in the literature that cues to action as a construct has not received the same level of empirical support as the other components of the HBM (Stretcher & Rosenstock, 1997; Champion & Skinner, 2008). The application of HBM constructs in this study is illustrated in Figure 3.2 below.

Figure 3.2. The application of the HBM to the current study.



3.6. Conclusion

In this chapter I introduced the foundational principles of the HBM, the theoretical framework that guided the conceptualisation of this study. I conducted a critical evaluation of the model in terms of its strengths and weaknesses, and provided a motivation for its relevance to mental health. Further, I outlined the way in which the HBM is appropriate for the research aims of this thesis against the backdrop of other theoretical models, and described how the HBM has been applied in the current study. Thus, this chapter has laid the theoretical foundation for the chapters to follow.

Chapter 4: Methodology

To preface this chapter, I restate my research aims and hypothesis below. Thereafter, I describe the methodology – in terms of the research design, recruitment and sampling strategy, measurement instruments and data analysis plan, as well as the relevant ethical considerations that were observed.

Quantitative data was collected in order to address the first research aim:

- To investigate whether HBM constructs significantly predict help-seeking intention among a group of South African adults with OCD.

To attend to the first research aim, the following hypothesis (H1) was tested:

- HBM constructs significantly predict help-seeking intention among a group of South Africa adults with OCD.

The null hypothesis (H0) is as follows:

- There is no relationship between HBM constructs and help-seeking intention among a group of South African adults with OCD.

In addition, a second research aim was addressed, namely:

- To determine the most endorsed barriers to help-seeking among a group of South African adults with OCD.

4.1. Research design

This study drew on a quantitative cross-sectional design, which is relevant to research aiming to investigate and quantify the relationship between variables (Singh, 2007). A battery of

online self-report surveys was administered to participants, which has been recommended as a timeous and structured way of collecting data (Bless, Higson-Smith, & Kagee, 2006).

4.2. Recruitment

This study formed part of ongoing OCD research conducted by the SA MRC Unit on Risk and Resilience in Mental Disorders at the Department of Psychiatry at SU. As such, participants were recruited from an existing database, and invited to participate by the co-director of that unit (Professor Christine Lochner). Inclusion criteria for the current study involved participants from the database who were 18 years and older, and who had obtained a lifetime diagnosis of OCD. Professor Lochner only reached out to participants whom she had comprehensively assessed in the last three years so that she could confirm that they had received a lifetime diagnosis of OCD. This diagnosis had been made using the Structured Clinical Interview for the DSM-5 (SCID-5), which is regarded as the gold standard in diagnosing DSM-5 psychiatric disorders (Brodey et al., 2018). Thus, this study made use of a purposive sampling technique, whereby participants are selected for having specific characteristics, based on the judgement of an expert (Etikan, 2016). For OCD diagnostic criteria according to the DSM-5, refer to Appendix 1.

Participant recruitment involved two phases. First, Professor Lochner extended a study invitation to potential participants via email (Appendix 2). This email included an explanation of the study, and requested permission for me to contact those who were interested. Once interest was indicated and permission obtained, I then made contact with participants via email (Appendix 3), sharing further study information and a link to the online survey. The survey included an online information page as a first step, requiring the submission of informed consent as a prerequisite for beginning the survey (Appendix 4).

4.3. Participants and sample

Participants were recruited from across South Africa. Professor Lochner reached out to approximately 92 people between 21 September and 10 November 2020, and a total of 54 participants agreed to be contacted. Of the 54 participants who agreed to be contacted, only 50 completed the survey, despite multiple follow-ups with those who failed to complete the survey. A power analysis was calculated a-priori using G-power software, which showed that a sample of $n=46$ was required to achieve acceptable power (0.80) with a correlation of 0.4. Descriptive statistics for the sample are presented in chapter 5.

4.5. Measures

This study made use of a battery of online self-report surveys, expected to take approximately 30 minutes. The scales used in the survey are described below.

4.5.1. Socio-demographics. To determine socio-demographic information, participants were asked to complete a short questionnaire indicating gender, age, and highest level of education. For the socio-demographic survey refer to Appendix 5.

4.5.2. Symptom severity. Symptom severity was measured using the Florida obsessive-compulsive inventory (FOCI) severity scale, which is a five-item, self-report scale offering a quick, yet effective assessment measure of the severity of OCD symptoms (Storch et al., 2007). The FOCI is based on the Yale-Brown Obsessive-Compulsive Scale-Self Report (Y-BOCS-SR), but is quicker to complete, estimated to take under five minutes. The scale involves five items measuring symptom severity, namely

- 1) frequency of obsessions and compulsions
- 2) distress
- 3) control over symptoms
- 4) degree of avoidance, and

5) level of daily interference.

Items are rated on a scale from 1 (no symptoms), 2 (mild symptoms), 3 (moderate symptoms), 4 (severe symptoms) to 5 (extremely severe symptoms). Higher scores indicate more severe OCD symptomatology. The measure has demonstrated good concurrent validity and strong internal consistency in other studies (Saipanish, Hiranyatheeb, & Lotrakul, 2015; Storch et al., 2007), with Cronbach's alpha levels ranging from 0.89 to 0.92. In the current study, the Cronbach's alpha reliability coefficient was adequate ($\alpha = 0.82$). For the FOCI, refer to Appendix 6.

4.5.3. Perceived treatment benefits. Perceived treatment benefits was measured using the Attitudes Toward Seeking Professional Psychological Help Scale-Short Form (ATSPPH-SF; Fischer & Farina, 1995), which is a 10-item scale designed to evaluate attitudes toward psychological treatment. The ATSPPH-SF examines three core dimensions to assess perceptions of treatment benefits, namely "Openness to seeking professional help," "Value in seeking professional help," and "Preference to cope on one's own" (Picco et al., 2016 p.4). Participants are offered a range of hypothetical statements, such as *"If I were experiencing a serious emotional crisis at this point in my life, I would be confident that I could find relief with professional assistance"*, and asked to indicate their level of agreement on a scale of 1 (disagree) to 4 (agree). Higher scores indicate positive perceptions of treatment benefits.

The ATSPPH-SF is a shortened version of the 29-item Attitudes Toward Seeking Professional Psychological Help (ATSPPH) measure, which has strong psychometric properties, including good internal consistency (Cronbach's alpha $\alpha = 0.86$) and construct validity (Fischer & Farina, 1995). Psychometric properties of the shortened scale were originally shown to match those of the longer scale (Fischer & Farina, 1995), which is reinforced by psychometric support for the short scale across a range of studies (Picco et al.,

2016). In the current study, the Cronbach's alpha reliability coefficient was acceptable ($\alpha = 0.83$). For the ATSPPH-SF, refer to Appendix 7.

4.5.4. Treatment barriers. Treatment barriers were measured using the Barriers to Access Care Evaluation (BACE) scale, a comprehensive 30-item self-report instrument assessing barriers to mental health care, with a particular focus on stigma barriers (Clement et al., 2012). The scale was developed and validated by expert researchers at King's College London (KCL), who identified the need for a thorough instrument assessing barriers to professional psychological services (Clement et al., 2012). The scale presents a range of barriers to mental healthcare, and participants are required to indicate whether any of the items prevent, delay, or discourage them from accessing professional care, on a scale of 1 (not at all) to 4 (a lot). Barriers include stigma and discrimination (i.e., "*concern that I might be seen as crazy*"), as well as structural barriers (i.e., "*not being able to afford the financial costs*"), mental health literacy (i.e., "*wanting to solve the problem on my own*"), among others. The BACE is designed to be applicable to individuals at any stage in the help-seeking process. The scale has been utilised in a number of studies across various settings, including Nigeria (James et al., 2019), Brazil (Silva et al., 2013), and the UK (Salaheddin & Mason, 2016). It demonstrates good psychometric properties, including adequate test-retest reliability, as well as strong content and construct validity (Clement et al., 2012). For the BACE, refer to Appendix 8.

4.5.5. Self-efficacy. Self-efficacy was measured using the general self-efficacy scale (GSES; Schwarzer & Jerusalem, 1995), which is a 10-item self-report survey. The items on the scale are designed to assess self-efficacy, with a focus on positive self-beliefs and a sense of personal agency. The scale presents statements such as "*I can usually handle whatever comes my way*" and "*If I am in trouble, I can usually think of a solution.*". Participants are asked to indicate whether they resonate with items on a scale of 1 (not at all true) to 4

(exactly true). It is a unidimensional measure. The scale has strong internal consistency, with Cronbach's alpha reliability coefficients ranging between 0.76 to 0.90 across more than 20 studies, and has demonstrated good criterion-related validity (Schwarzer & Jerusalem, 1995). In the current study, the Cronbach's alpha reliability coefficient was acceptable ($\alpha = 0.89$). For the GSES, refer to Appendix 9.

4.5.6. Help-seeking intention. Participants were asked to rate their intention to seek professional help for OCD on a scale from 1 (very unlikely) to 5 (very likely), with higher scores indicating increased likelihood of seeking help. Specifically, participants were asked, "*How likely are you to seek help from a professional for OCD in the future?*". This one-item measure was based on a study conducted by Langley et al. (2017), which utilised a similar help-seeking assessment method. For the help-seeking measure, refer to Appendix 10.

4.5.7. Treatment history. To enrich our understanding of formal help-seeking experiences (i.e., from mental health clinicians such as psychologists or psychiatrists) within this sample, a short section inquiring about treatment history was included at the end of the survey. Participants were asked to indicate whether or not they had received treatment for their OCD in the past (yes or no). Participants who indicated "yes" were presented with follow-up questions inquiring about the type of treatment sought, as well as the level of symptom change following treatment, measured using the Clinical Global Impression–Improvement scale (CGI-I) (Busner & Targum, 2007). Participants who indicated "no" were directed to the end of the survey. For the treatment history measure, refer to Appendix 11.

4.6. Data analysis

I used the Statistical Package for Social Sciences (SPSS) version 27 to analyse the data, with the guidance of a senior statistician at SU. First, the dataset was screened to ensure that no variables were missing, and scale items were re-coded where necessary. Thereafter, the

parametric assumption of normality was checked by generating normal probability plots. To familiarise myself with the data, descriptive statistics were calculated for socio-demographics, treatment history, predictor variables, and the outcome variable. These descriptive statistics are presented in chapter 5.

The first research aim (i.e., to investigate whether HBM constructs significantly predict help-seeking intention among a group of South African adults with OCD) was addressed by investigating the relationship between the predictor variables and the outcome variable. This was done initially by calculating Pearson's product-moment correlation coefficients, to determine the strength of association between variables (Clark-Carter, 2018). Next, multiple linear regression analysis was performed to investigate the contribution of predictor variables to the variance in the outcome variable (Clark-Carter, 2018). Regression assumptions of normality, homoscedasticity and multicollinearity were checked, and the significance level set at $\alpha=0.05$. A frequency table was generated to examine detailed responses regarding barriers to help-seeking, as well as a histogram to determine the top four barriers, in response to the second research aim (i.e., to determine the most highly endorsed barriers to help-seeking among a group of South African adults with OCD).

4.7. Ethical considerations

I obtained ethical approval from the Human Research Ethics Committee on 10 September 2020 (Appendix 12), and approval of a minor amendment involving an update to the study title and survey content on 21 September 2020 (Appendix 13). Data collection commenced thereafter. I paid attention to a number of key ethical considerations when conducting my study, described in further detail below.

4.7.1. Informed consent. Informed consent has been characterised as the cornerstone of human rights protections (Marczyk, DeMatteo, & Festinger, 2010) and is a prerequisite for

conducting psychological research. Accordingly, participants were presented with an information and consent form for online surveys (Appendix 4) that they were required to read and comply with before proceeding with the survey. The form provided a description of the study and the research aims, in non-technical terms. In addition, it communicated the reasons that the participants had been selected, and the amount of time expected to complete the survey (30 minutes). It was emphasised that participants could withdraw from the study at any time, without any negative consequences. To give participants an idea of what to expect from the survey, examples of survey questions were provided, as well as an outline of the benefits and risks of the study. Participants were offered an option to download the information form for safe keeping.

4.7.2. Benefits and risks. Potential benefits of participating in the study were conveyed to participants, in that they might enjoy completing the survey, and might discover something new about their condition and their help-seeking patterns. Indeed, many participants reached out via email following the completion of the survey to indicate that they had enjoyed participating in the process. It was communicated that the study would help researchers better understand help-seeking among adults with OCD in South Africa, with the ultimate aim of addressing factors that may affect illness outcome. Participants had the option to enter into a lucky draw to win a cash prize of R2000 as a reward for their time, by entering their email address at the end of the survey. Of the 50 participants who completed the survey, 45 signed up for the lucky draw, and a winner was randomly drawn from a hat following data collection. Potential risks were outlined to participants, namely that they might feel uncomfortable sharing information about their personal help-seeking intentions. Participants were informed that their involvement was entirely voluntary, and that they had the option of withdrawing at any time without consequences of any kind.

4.7.3. Adverse psychological reactions. Given that this study involved a vulnerable population, arrangements were made to ensure that relevant treatment referrals were available in case participants experienced any distress during (or as a result of) the survey. An existing treatment referral system exists for the larger study in the SA MRC Unit on Risk and Resilience in Mental Disorders, to which this study had access. No participants requested treatment referrals or indicated any adverse psychological reactions as a result of their participation.

4.7.4. Confidentiality and anonymity. Survey responses were automatically anonymised, and as such participant responses remained confidential at all times. The data was only accessed by me, my main research supervisor (Professor Lochner), and the senior statistician at SU. All data collected in connection with this study was stored securely, on an access-controlled, password-protected database.

4.7.5. Thank you form. A thank you form (Appendix 14) was shared with participants at the end of the survey, confirming that they qualified for a cash prize as a reward for their time, and reiterating the rationale for the study. The form included my name and email address as well as that of Professor Lochner, and indicated that participants could contact us if they had any questions or concerns about the study (Hathorn / Lochner), or if they experienced any discomfort and required treatment referrals (Lochner).

Chapter 5: Results

In this chapter I first present an overview of sample characteristics followed by relevant descriptive statistics, and then the corresponding inferential statistics. In doing so, both the first and second research aims are addressed.

5.1. Sample Characteristics

This section provides summary statistics of key sample characteristics, including socio-demographics and treatment background. A total of 50 participants (n=50) volunteered to be involved in this study. All participants had been involved in prior research with the SA MRC Unit on Risk and Resilience in Mental Disorders and were diagnosed with lifetime OCD (i.e. current and past OCD).

5.1.1. Socio-demographics. The average participant age was 36.5 years old, with ages ranging from 19 to 59 years. The majority of the sample (58%) had obtained education at university level. More women (58%) than men (42%) were involved in the study. These socio-demographic characteristics are summarised in Table 5.1 below.

Table 5.1. Socio-demographic characteristics of the sample

	n	%	f	M	SD	Range
Age (years)	50			36.5	9.65	19–59
Education	50					
University degree(s)		(58)	29			
College / Technikon diploma		(14)	7			
Grade 11–12		(26)	13			
Grade 8–10		(2)	1			
Gender	50					
Women		(58)	29			
Men		(42)	21			

5.1.2. Treatment history. The majority of participants in the sample (n=46, 92%) had sought formal treatment in the past, and of these participants, 70% had engaged with treatment involving a combination of medication and psychotherapy. Further, CGI-I scores indicated that 50% of participants reported that their symptoms were much improved as a result of treatment. This information is summarised in Table 5.2. below.

Table 5.2. Treatment history

	n	(%)	f
Treatment sought	50		
Yes		(92)	46
No		(8)	4
Treatment type	46		
Medication		(20)	9
Psychotherapy		(7)	3
Medication & psychotherapy		(70)	32
Other		(4)	2
Symptom change with treatment	46		
Very much improved		(15)	7
Much improved		(50)	23
Minimally improved		(26)	12
No change		(7)	3
Minimally worse		(0)	0
Much worse		(2)	1

5.2. Data screening and reliability of measures

No values were missing from the data set. In order to assess the parametric assumption of normality, normal probability plots were generated. Observations followed an approximate straight line for each variable, indicating acceptable normality.

Reliability of scales was determined by assessing internal consistency, or the ability of a test to measure an underlying construct in the same way (Tavakol & Dennick, 2011). Internal consistency was assessed for scales measuring predictor variables by calculating the Cronbach's alpha reliability coefficient for instruments, where applicable. Guidelines suggest that a Cronbach's alpha reliability coefficient between 0.70 and 0.90 indicates an acceptable level of reliability (Tavakol & Dennick, 2011). As shown in Table 5.3, an adequate Cronbach's alpha reliability coefficient was calculated for symptom severity, treatment benefits, and self-efficacy. It was not necessary to calculate the Cronbach's alpha reliability coefficient for treatment barriers, given that it is a formative construct – whereby the scale items inform the construct (Cenfetelli & Bassellier, 2009).

Table 5.3. Cronbach's alpha reliability coefficients for predictor variables

	α
Symptom severity	0.82
Perceived treatment benefits	0.83
Self-efficacy	0.89

5.3. Regression assumptions

Before multiple regression analysis was performed, I tested the four assumptions of multiple linear regression. The first includes the assumption of normality, whereby the residuals of the regression should be normally distributed (Osborne & Waters, 2002). This was determined by generating a normal P-Plot and examining the spread of data points in relation to the normal line (see Figure 5.2 below). Although there is some deviation, the majority of residuals follow the straight line, thus satisfying the assumption of normality.

The second assumption includes the assumption of homoscedasticity, whereby the variance in error terms is consistent (Osborne & Waters, 2002). The violation of homoscedasticity is heteroscedasticity – or unequal variance in error terms – which produces a characteristic cone shape in residual plots (Olvera Astivia & Zumbo, 2019). The absence of heteroscedasticity is confirmed in Figure 5.3 below, indicating a random pattern of data points which are relatively equally distributed above and below zero on the X and Y axis.

The third assumption is that of no multicollinearity, meaning that predictor variables should not be strongly inter-correlated. This assumption was tested by examining the variance inflation factors (VIF) of items for predictor variables. As a rule of thumb, VIF scores greater than a level of 5 indicate unacceptable multicollinearity. As demonstrated by Table 5.6, VIF scores did not exceed 1.69 across constructs, thus satisfying the assumption of no multicollinearity.

The fourth and final assumption is that of linearity, which is satisfied if the assumptions of normality and homoscedasticity have been met.

Figure 5.1. Normal P-Plot demonstrating normality of residuals

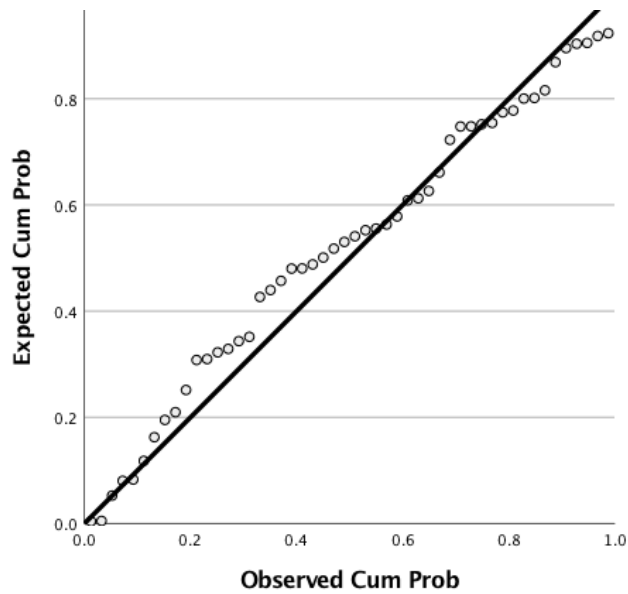


Figure 5.2. Scatterplot demonstrating homoscedasticity of residuals

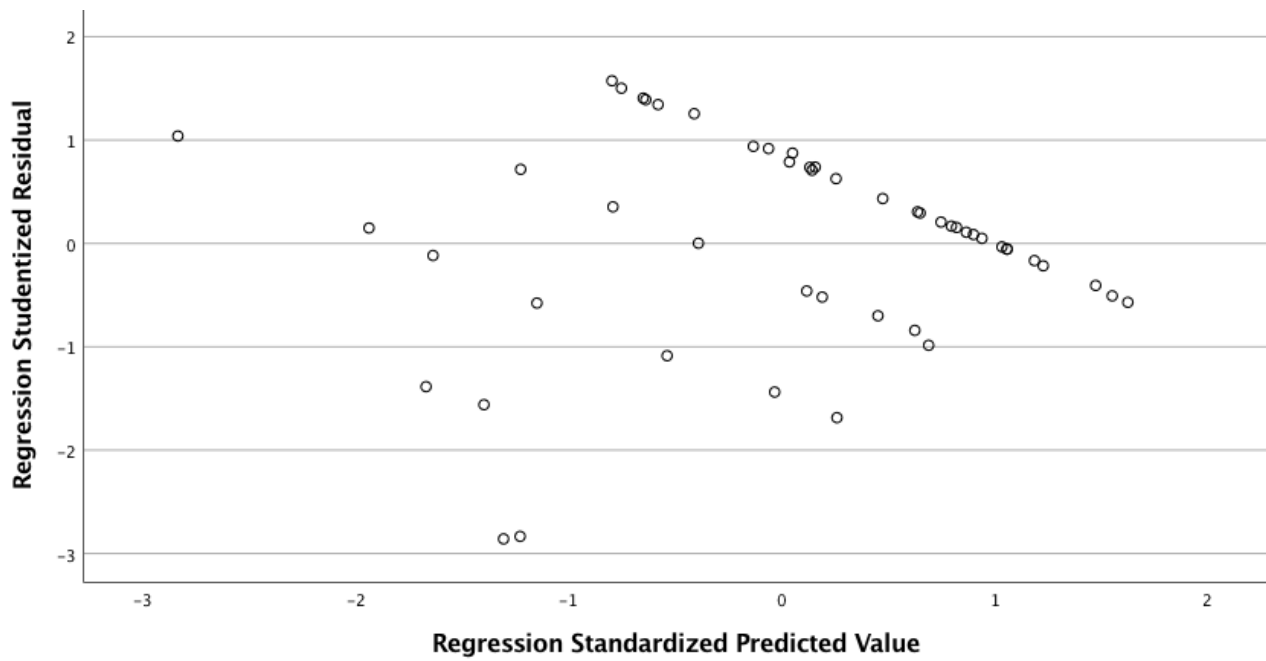


Table 5.4. Variance inflation factors (VIF) of items for predictor variables

Variable	VIF
Age	1.24
Gender	1.37
Education	1.68
Symptom severity	1.69
Perceived treatment benefits	1.51
Treatment barriers	1.64
Self-efficacy	1.39
[n=50]	

5.4. Descriptive statistics

Descriptive statistics were calculated for predictor variables and the outcome variable, and are summarised in Table 5.4. On average, participants in this sample reported moderate to severe OCD symptoms ($M = 3.12$), medium to high self-efficacy ($M = 2.75$), positive perceptions of treatment benefits ($M = 3.20$), and moderate level barriers to treatment ($M = 2.00$). In addition, on average, participants showed high levels of help-seeking intention ($M = 4.28$).

Table 5.5. Descriptive statistics

FOCI Symptom Severity [Scale 1-5]	Mean	3.12
	SD	0.70
GSES Self-efficacy [Scale 1-4]	Mean	2.75
	SD	0.54
ATSPPH-SF Perceived treatment benefits [Scale 1-4]	Mean	3.20
	SD	0.60
BACE Treatment barriers [Scale 1-4]	Mean	2.00
	SD	0.54
Help-seeking intention [Scale 1-5]	Mean	4.28
	SD	1.10

[n=50]

5.5. Predictors of help-seeking intention

To address the first research aim, namely “to investigate whether *HBM* constructs significantly predict help-seeking intention among a group of South African adults with *OCD*”, the relationship between predictor variables and the outcome variable was investigated. To do this, Pearson’s product-moment correlation coefficients were calculated, and multiple linear regression analysis was performed.

5.5.1 Correlations between *HBM* constructs and help-seeking intention. Pearson’s product-moment correlation coefficients were calculated to determine the nature and strength of relationships between *HBM* constructs and help-seeking intention. These results are described below and summarised in Table 5.7.

5.5.1.1. Socio-demographics. No significant correlations were found between help-seeking intention and age ($r = -0.03$, $p = 0.85$), gender ($r = -0.14$; $p = 0.32$) or education ($r = 0.002$, $p = 0.99$), respectively.

5.5.1.2. Symptom severity. No significant correlations were found between help-seeking intention and OCD severity ($r = -0.06$, $p = 0.67$).

5.5.1.3. Perceived treatment benefits. A significant positive correlation was found between help-seeking intention and perceived treatment benefits ($r = 0.58$, $p = <0.01$).

5.5.1.4. Treatment barriers. No significant correlations were found between help-seeking intention and treatment barriers ($r = 0.06$, $p = 0.67$).

5.5.1.4. Self-efficacy. No significant correlations were found between help-seeking intention and self-efficacy ($r = -0.13$, $p = 0.38$).

Table 5.6. Correlations between HBM constructs and help-seeking intention

	r	p
Age	-0.03	0.85
Gender	-0.14	0.32
Education	0.002	0.99
Symptom severity	-0.06	0.67
Perceived treatment benefits	0.58	<0.01**
Self-efficacy	-0.13	0.38
Treatment barriers	-0.06	0.67

[n=50] **Correlation is significant at the 0.01 level | (2-tailed)

5.5.2 Regression results. Multiple regression analysis was performed in order to better understand whether the combination of all HBM constructs assessed here (i.e., socio-demographics, symptom severity, self-efficacy, perceived treatment benefits and treatment barriers) predict help-seeking intention. The regression results indicate that 42.6% of the variance in help-seeking intention can be explained by the predictors in the regression model ($R^2 = 0.426$, $F(7,42)=4.45$ $p<0.01$), with a moderate multiple regression coefficient ($R = 0.65$). In keeping with the correlation results, *perceived treatment benefits* was the only predictor variable that significantly predicted help-seeking intention ($B=1.37$, $t(42)= 5.16$), $p<0.01$). Thus, given that perceived treatment benefits accounted for 42.6% of the variance in the outcome variable, and the null hypothesis (H_0) – stating no significant relationship between predictors and the outcome variable – can be rejected. The regression results are summarised in Table 5.8 below.

Table 5.7. Regression results for outcome variable: help-seeking intention

	β	$SE\beta$	B	SEB	$t(42)$	p
Intercept			-1.47	2.5	0.59	0.56
Age	-0.06	0.13	-0.01	0.01	-0.48	0.64
Gender	0.03	0.14	0.07	0.3	0.23	0.82
Education	0.12	0.15	0.15	0.18	0.82	0.42
Symptom severity	0.15	0.15	0.24	0.24	1	0.32
Perceived treatment benefits	0.74	0.14	1.37	0.26	5.16	<0.01
Self-efficacy	-0.14	0.14	-0.28	0.28	-.99	0.33
Treatment barriers	0.2	0.15	0.41	0.31	1.34	0.19

[n=50]

5.6. Barriers to help-seeking

Figure 5.1 below depicts the top four barriers to help-seeking, in response to the second research aim, namely, “*To determine the most endorsed barriers to help-seeking among a group of South African adults with OCD*”. These barriers include 1) wanting to handle the problem independently, 2) treatment concerns, 3) lack of finances, and 4) embarrassment and shame factors. Table 5.9 demonstrates a more detailed overview of all barriers to help-seeking reported in the current study.

Figure 5.3. Top four barriers to help-seeking in the current study

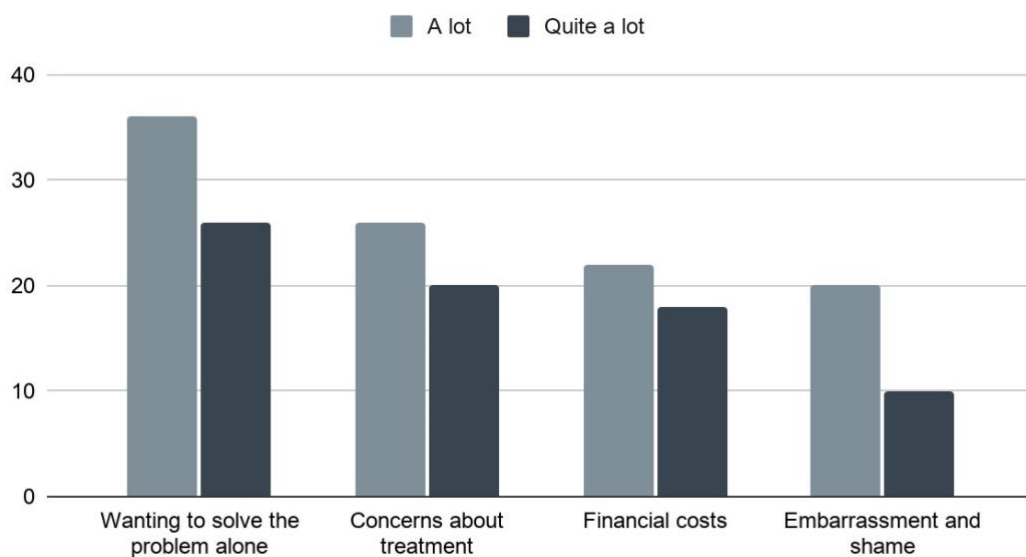


Table 5.8. A detailed description of all barriers to help-seeking

Barrier	Not at all (%)	A little (%)	Quite a lot (%)	A lot (%)	
Being unsure where to go for professional care	40	28	24	8	
Wanting to solve the problem on my own	10	28	26	36	
Concern that I might be seen as weak for having a mental health problem	32	24	18	16	
Fear of being put in a hospital against my will	56	26	6	12	
Concern that it might harm my chances when applying for jobs	56	24	8	12	
Problems with transport or travelling to appointments	72	22	4	2	
Thinking the problem would get better by itself	24	40	20	16	
Concern about what my family might think, say, do, or feel	48	20	16	16	
Feeling embarrassed or ashamed	32	28	10	20	
Not being able to afford the financial costs involved	28	32	18	22	
Preferring to get alternative forms of care (e.g., traditional healing)	52	36	6	6	
Concern that I might be seen as ‘crazy’	54	26	12	8	
Thinking professional care probably would not help	34	38	14	14	
Concern that I might be seen as a bad parent	36	8	4	10	<i>N/A (%): 42</i>
Being too unwell to ask for help	66	16	12	6	
Professionals from my own ethnic or cultural group not being available	86	12	2	0	
Concern that people I know might find out	50	32	10	8	
Dislike of talking about my feelings, emotions or thoughts	38	32	14	16	
Concern that others might not take me seriously if they found out	52	26	14	8	
Concerns about the treatments available (e.g., medication side effects)	34	20	20	26	
Previous bad experiences with professional care for mental health	54	28	10	8	
Not wanting a mental health problem on my medical records	52	24	6	18	
Preferring to get help from family or friends	52	30	14	4	
Concern that my children may be taken into care without my agreement	44	10	2	0	<i>N/A (%): 44</i>
Thinking I did not have a problem	48	40	8	4	
Concern about what my friends might think, say or do	62	26	4	8	
Difficulty taking time off work	48	24	14	14	
Having problems with childcare while I receive professional care	46	2	4	2	<i>N/A (%): 46</i>
Concern about what people at work might think, say or do	48	24	10	18	
Having no one who could help me get professional care	68	28	2	2	

Chapter 6: Discussion and conclusion

The aims of this study were two-fold: first, to investigate whether HBM constructs significantly predict help-seeking intention among a group of South African adults with OCD, and second, to determine the most endorsed barriers to help-seeking for OCD in this sample. The main finding was that perceived treatment benefits significantly predicted help-seeking intention, whereas the other HBM constructs (treatment barriers, severity, self-efficacy, and socio-demographics) did not. Primary help-seeking barriers in this sample included 1) wanting to handle the problem independently, 2) treatment concerns, 3) lack of finances, and 4) embarrassment and shame factors.

6.1. HBM constructs as predictors of help-seeking

As outlined in chapter three (theoretical framework), the HBM posits that individuals will engage with health services if they believe the illness is severe and threatening, that there are many benefits and few barriers to treatment, and if they feel they have a strong sense of personal self-efficacy, i.e., believing in one's capacity to successfully accomplish a task or achieve a goal (Bandura, 1977a). The findings in the current study partially lend support to the utility of the HBM, with the regression model involving HBM constructs (symptom severity, perceived treatment benefits, treatment barriers, self-efficacy) predicting 42.6% of the variance in the outcome variable (help-seeking intention) in the sample of South African adults with OCD. Perceived treatment benefits was the only HBM construct of significance, however, highlighting the strength of this variable as a predictor of help-seeking intention in this model.

6.1.1. Perceived treatment benefits. The significance of perceived treatment benefits in this case echoes the results of other similar studies that have applied the HBM to mental health contexts (e.g. Langley et al., 2017, O'Connor et al., 2014). Both Langley et al. (2017) and O'Connor et al. (2014) found perceived treatment benefits to be a strong predictor of help-seeking intention for other mental health concerns, namely generalised anxiety disorder and general psychological distress, respectively. Theoretically, these results considered together endorse the utility of perceived treatment benefits as a construct within the HBM.

It is relevant to note that both of these prior studies (e.g. Langley et al., 2017; O'Connor et al., 2014) were conducted in Australia, a developed country where public access to psychological services is funded by Medicare, the national health insurance scheme (Langley et al., 2017). Thus, Australian residents have access to mental health care in such a way that is markedly different for the South African population, the majority of whom are uninsured and often not able to access psychological services (Docrat et al., 2019). In this way, it can be suggested that perceived treatment benefits are linked to help-seeking intention across diverse settings and health systems.

Studies focusing on help-seeking for OCD specifically have also demonstrated similar results (e.g., Belloch et al., 2008; Robinson et al., 2017), suggesting that positive beliefs about OCD treatment correlate with help-seeking processes. In these studies, positive beliefs about treatment were associated with having prior (accurate) knowledge about OCD treatment, confidence in mental health practitioners, and positive information about psychological services by way of the media and word-of-mouth (Belloch et al., 2008; Robinson et al., 2017). In the current study, positive perceptions of treatment were measured by the ATSPPH-SF scale, focusing on *general* attitudes about the effectiveness of professional help in assisting with psychological problems with participants endorsing scale items such as “*If I believed I was having a mental breakdown, my first inclination would be*

to get professional attention". Positive perceptions of treatment in this case may have been influenced by patients having treatment experiences in the past, which is supported by literature highlighting that prior help-seeking history significantly predicts future help-seeking intention for mental illness across cultural groups (Chen & Mak, 2008). In the current study, the treatment history data indicated that the majority of the sample had engaged with prior treatment, and 50% of this group had improved with treatment according to the CGI-I scale, suggesting that many participants would have had positive treatment experiences. This reasoning is further supported by the data collected in the BACE scale, which showed that only a very small percentage (8%) of the sample endorsed "previous bad experiences with professional care for mental health" as a significant barrier to seeking help for their OCD. Although treatment history was not an HBM construct and therefore was excluded from the regression model in this case, future research could test this relationship and verify the contribution of prior treatment to help-seeking intention among adults with OCD in this setting.

On a practical level, it is possible that this result calls attention to the role of mental health literacy in relation to OCD and spotlights the importance of psychoeducation focused on treatment, which may encourage more positive beliefs about psychological treatment for OCD. Notably, a body of literature demonstrates that public general knowledge regarding OCD is generally poor (Coles et al., 2013; Fennell & Liberato, 2017; Stewart et al., 2019), thus reinforcing the need for public psychoeducation.

Research has shown that education alone can play a fundamental role in encouraging patient motivation and engagement with OCD treatment. In many cases, patients feel empowered by learning about the functional features of their obsessions and compulsions, and in understanding how treatment directly addresses this dysfunction (Abramowitz & Siqueland, 2013). As an example, it can be helpful for patients to understand that although

compulsions may relieve anxiety associated with obsessions in the short term, they ultimately perpetuate obsessions at the cost of freedom in the long term (Abramowitz & Siqueland, 2013). This knowledge and insight can help patients to make sense of their condition and trust in the validity of the treatment process, thus encouraging processes of help-seeking.

In this way, the significance of perceived treatment benefits in the current study points to themes about education and mental health literacy in relation to OCD that have emerged in the wider literature. It can be suggested that educating the public about OCD and the efficacious, evidence-based sources of help and treatment – in terms of their benefits and how they address the psychopathology of OCD – may encourage help-seeking and improve illness outcome. Notably, South African research has emphasised the importance of attitudes, beliefs, and knowledge in relation to mental health service utilisation (Bantjes et al., 2020). Thus, recommendations to improve mental health literacy relating to OCD in this setting may involve marketing and media campaigns that target widely held beliefs about OCD and advocate treatment benefits. An alternative avenue may involve psychoeducation programmes targeting individuals, families, and wider communities (Petersen & Lund, 2011).

6.1.2. Treatment barriers. The present study found no significant relationship between help-seeking intention and HBM constructs other than perceived treatment benefits. Treatment barriers in particular appeared to predict help-seeking intention in several mental health studies (e.g. Kim & Zane, 2016; Nobling & Maykrantz, 2017; O'Connor et al., 2014) although it emerged as insignificant in others (e.g., Langley et al., 2017). Despite the fact that data from the BACE scale indicated that participants experience a range of different barriers to help-seeking, this HBM construct did not contribute significantly to the regression model in the current study. In this regard, Langley et al., (2017) suggested that “it is not the *quantity* of barriers, but *quality* of barrier that may be important predictors of help-seeking intention” (p.7) and a similar hypothesis may be explored here. Nevertheless, further inquiry

is warranted in order to better understand the nature and quality of help-seeking barriers among adults with OCD in South Africa. A more detailed discussion of the barriers that were most frequently endorsed in the current study is provided in section 6.2. below.

6.1.3. Symptom severity. The finding that symptom severity did not contribute significantly to help-seeking intention deserves comment, as this is inconsistent with a body of research suggesting that increased OCD symptom severity is associated with service-use (Besiroglu et al., 2004; Cullen et al., 2008; Mayerovitch et al., 2003; Ruscio et al., 2010) and contrary to the idea that individuals who are in greater distress or more functionally impaired are more likely to seek help. It may be possible that, in some cases, greater levels of distress may impede help-seeking for OCD, for example when individuals are too impaired to seek help, or too avoidant. Indeed, avoidance is one of the fundamental features of OCD (American Psychological Association, 2013).

From the perspective of the HBM, the non-significance of the severity construct in relation to help-seeking intention reflects a conversation where authors have criticised the explanatory strength of symptom severity, due to its weak predictive power in other studies (Carpenter, 2010; Langley et al., 2017; Skinner et al., 2015).

6.1.4. Self-efficacy. Consistent with other mental health studies utilising the HBM to predict mental health help-seeking (e.g. Connor et al., 2014; Langley et al., 2017), self-efficacy did not contribute significantly to the variance in help-seeking intention. These findings considered together call into question the usefulness of this HBM variable in relation to help-seeking for mental health problems. It is also worthwhile to critically consider the nature of self-efficacy as a construct, defined by Bandura (1977a) as “the conviction that one can successfully execute the behaviour required to produce the required outcome” (p193). As such, it is possible that this construct is more relevant to studies investigating *behaviour* rather than *intention*. However, Skinner et al., (2015) noted that no systematic reviews have

assessed whether the inclusion of self-efficacy (as a more recent component of the HBM) increases the predictive strength of the model, and that “this is an important gap” (p.106). Further investigation into whether this construct contributes meaningfully to the predictive power of the HBM is therefore warranted.

6.1.5. Socio-demographics. Finally, socio-demographic variables did not contribute significantly to the model, which is consistent with some literature demonstrating no relationship between socio-demographics and help-seeking for OCD (e.g. Besiroglu & Agarun, 2006), although other studies have highlighted a correlation (Subramaniam et al., 2013). Age in particular has been shown to influence OCD service-use, with increased age being associated with help-seeking delays (Millet et al., 2004; Stengler et al., 2012). Accordingly, Cullen et al., (2008) found that participants under the age of 60 were more likely to seek help for their OCD, reflecting global mental health research highlighting that younger individuals are more likely to seek help for common mental health disorders (Roberts et al., 2018). In contrast, age did not contribute significantly to help-seeking intention in the current study, despite a relatively large age range within participants (19 – 59 years).

Prior studies applying the HBM to mental health problems have also yielded mixed results regarding the influence of socio-demographic factors. For example, O'Connor et al., (2014) demonstrated no relationship between socio-demographics and help-seeking for mental health concerns, while Kim and Zane (2016) found that ethnicity significantly influenced help-seeking intention in their application of the HBM to psychological distress in a sample of American students. Langley et al., (2017) found that gender significantly predicted help-seeking intention in their application of the HBM to anxiety disorders, with women being more likely to seek help compared to men.

Recent research in South Africa has also highlighted that socio-demographic variables played a key role in mental health treatment utilisation in a cohort of university students (Bantjes et al., 2020), with factors such as race, gender, and sexual orientation significantly influencing treatment seeking. Against this backdrop, it is somewhat surprising that socio-demographics were not statistically significant in this study, although not inconceivable given the mixed results in the literature.

To summarise, these results suggest that the HBM is partially useful in predicting a degree of help-seeking intention among a group of adults in South Africa, although the findings have also raised a number of questions regarding HBM constructs which may be further explored in future research. Strikingly, these findings emphasise the importance of beliefs about OCD treatment in influencing help-seeking intention among adults with OCD within this setting, with important implications for psychoeducation and mental health literacy.

6.2. Help-seeking barriers

The second research aim of the present study was to determine the most endorsed barriers to help-seeking among a group of South African adults with OCD. Although treatment barriers did not significantly predict help-seeking intention in the regression model, data collected using the BACE scale offers insight into a comprehensive range of barriers to help-seeking in this setting which is worth commenting on.

6.2.1. Barrier 1: *Desire to manage symptoms independently.* The most endorsed help-seeking barrier in our sample included “Wanting to solve the problem on my own”, mirroring an Australian study (Gentle, Harris, & Jones, 2014) where this also emerged as the most highly endorsed barrier to seeking help for OCD. Similarly, Goodwin et al., (2002)

found that a significant percentage of American adults with OCD (28.4%) endorsed a preference for self-reliance as a barrier to treatment.

While further investigation is necessary in order to understand the reasons why patients with OCD prefer to handle their problems independently, some inferences can be made based on the results of the current study and existing literature. For example, it is plausible to suggest that the desire to deal with OCD symptoms privately may relate to the strong degree of secrecy that is associated with the condition, reflecting a large body of research highlighting the role of secrecy in inhibiting help-seeking for OCD (e.g. Belloch et al., 2008; Glazier et al., 2015; Robinson et al., 2017). Secrecy in OCD has also been linked to shame factors in the literature (e.g. Brooks, 2011) and it is thus possible that, in the current sample, participants' preference for self-reliance might be explained by shame and embarrassment, which also emerged as an important barrier to help-seeking in this study. Indeed, all of the highly endorsed help-seeking barriers in this study – namely lack of finances, shame, and concerns about treatment – can be considered meaningful reasons for wanting to handle OCD symptoms without formal help.

A preference for self-reliance has also emerged as a theme in studies focusing on other mental health problems, in other settings. For example, Kessler et al., (2001) found that 72% of participants with serious mental illness in their USA-based sample failed to seek treatment on account of wanting to solve their problem on their own. Similarly, a systematic review of mental health help-seeking barriers among Chinese adults reported that a preference for self-sufficiency was a key theme (Shi, Shen, Wang, & Hall, 2020). Moreover, the World Mental Health International College Student (WMH-ICS) initiative highlighted that more than half (56.4%) of college students expressed a preference for handling an emotional problem alone, as a barrier to future help-seeking (Ebert et al., 2019). Therefore, while it can be inferred that this help-seeking barrier is important and problematic for

individuals with OCD – based on the current result in conjunction with that of Gentle et al. (2014) and Goodwin et al. (2002) – it cannot be determined whether this barrier is *more* relevant to OCD compared to those involving other mental health conditions. Further research is necessary in order to determine whether this barrier relates to OCD-specific features (such as secrecy and privacy) or whether it is the product of more general mental health concerns, such as stigma. It is also highly plausible that both arguments apply, in that a combination of illness-related factors as well as general mental health concerns may contribute to a preference for self-reliance in OCD. An enhanced understanding of the reasons *why* some individuals with OCD may prefer to handle their problems on their own will aid in understanding this barrier, and serve to address it as a way of improving access to formal help.

6.2.2. Barrier 2: Concerns about treatment. The second most endorsed help-seeking barrier in this study was “concerns about treatments available, e.g., medication side-effects”, which is not an uncommon phenomenon in relation to psychological treatment, particularly psychiatric medication (Marrero, Fumero, De Miguel, & Penate, 2020). There is a growing appreciation in the literature that individuals diagnosed with psychiatric disorders often have diverse and complex beliefs about medication, ranging from pharmacophobia, i.e., fear and mistrust of medication (Petelinsek & Korajlija, 2020), to those who feel that medication is a hindrance (Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009). Beliefs about treatment have an impact not only on help-seeking, but also on treatment motivation and adherence in the longer term, with implications for illness outcome. In many cases, fears about medication are fuelled by popular myths about the negative side-effects of psychiatric medications – including sedative effects, weight gain, and personality changes – which are largely untrue, particularly in relation to the newer SSRIs (Phan, 2020).

Concerns about treatment may extend beyond medication and include fears and reservations regarding psychotherapy for OCD, particularly ERP exposure exercises. Such exercises would involve exposing patients to obsessional triggers and cues so that they can learn to withhold compulsive rituals and break the obsessive-compulsive cycle (Franklin & Foa, 2011). Many OCD patients spend much of their time avoiding obsessional cues at all costs, and therefore the prospect of undergoing an experience that actively induces obsessions would naturally be frightening for such individuals. This notion is supported by research confirming that avoidance behaviours, which are common among individuals with OCD, also often extend to treatment avoidance (Wheaton, Gershkovich, Gallagher, Foa, & Simpson, 2018). This in turn has an impact on treatment outcome, as avoidant individuals have shown to be less likely to achieve remission following ERP treatment (Wheaton et al., 2018). Other factors that may contribute to concerns about psychotherapeutic treatment for OCD may include worries about the intensive and arduous nature of ERP therapy, which involves considerable effort on behalf of the patient in the form of homework exercises and a commitment to frequent and often anxiety-provoking appointments (Maltby & Tolin, 2005). Moreover, Williams et al. (2012) found that patients with OCD expressed fears about their ability to remain committed to the therapy process, and that this emerged as a primary help-seeking barrier among participants. Similarly, Marques et al. (2010) highlighted that concerns about treatment, specifically doubts about treatment effectiveness, was a common barrier to help-seeking and service use for OCD.

Given the nature of OCD, which is characterised by anxiety and distorted cognitive appraisals such as exaggeration of threat and intolerance for uncertainty (Abramowitz, & Siqueland, 2013), it is unsurprising that concerns and fears surrounding treatment would exist. All things considered, this barrier reinforces the call for psychoeducation to address myths and quell fears surrounding psychological treatment and care. Psychoeducation should

aim to demystify the OCD treatment process, increasing access to practical information regarding how a diagnosis is made, what psychotherapeutic treatment entails, realistic expectations of medication side effects, and highlighting sources of suitable help for locals. Arguably, increased psychoeducation and mental health literacy should diffuse untruths about the condition and treatment, enhance help-seeking intention and behaviour, and ultimately improve outcome.

6.2.3. Barrier 3: Concerns about costs. The third most endorsed help-seeking barrier in the current study included “I was worried about the cost”. As described in chapter two, specialised psychological services – including psychologists specialising in CBT with ERP – are generally located within the private sector in South Africa (Docrat et al., 2019). On average, a single appointment with a private psychologist in South Africa costs approximately R1000 for a 50-minute session, according to the National Health Reference Price List (NHRPL, 2020). Further, gold-standard guidelines for OCD treatment recommend that adults with mild to moderately impaired functioning should engage in more than ten therapist hours of ERP therapy, with the option of a course of SSRI medication (NICE, 2005). Thus, this means that adults with mild to moderate OCD in South Africa would be facing a cost of at least R10 000 for psychotherapeutic treatment alone. This cost would be even greater should they choose to engage with a course of SSRIs, which would involve an appointment with a GP (approximately R500 per session) or psychiatrist (approximately R1800 per session) to obtain a script, and this financial burden would be further compounded by the cost of medication (NHRPL, 2020). Considering these costs in relation to the current average monthly salary of an adult in South Africa, which was shown to be R21448 per month in the second quarter of 2020 (Trading economics, 2020), psychotherapeutic treatment would be considered costly and largely unaffordable for the average adult residing within this

setting. Thus, it is unsurprising that concerns about cost would be an endorsed structural barrier to help-seeking within this sample.

In chapter two, a number of structural barriers to formal help-seeking in South Africa were outlined, including affordability, transport, physical access, and system-level barriers such as incohesive service delivery and long waiting lists (Field et al., 2020; Smith et al., 2010) as well as urban and rural disparities, a complex national disease burden, among other challenges (Docrat et al., 2019). Against this backdrop, the expectation was that structural barriers would be salient within this study. However, the majority of endorsed help-seeking barriers in this study seemed to exist more in the individual or psychological domain (i.e., a preference for self-reliance, treatment concerns, and shame factors) rather than on a structural level. By the same token, the majority of the sample (72%) did not endorse lack of or difficulties around transport to treatment as a structural help-seeking barrier, in contrast to some other international studies (Glazier et al., 2015; Marques et al., 2010).

The few structural help-seeking barriers reported in this study might be explained by the socio-economic status (SES) of the sample, which – based on their education status – is likely higher than the wider community. Recent data shows that approximately only 7% of the adult population in South Africa is educated at the tertiary level (OECD, 2019); in contrast, the majority of the sample in the present study (72%) had obtained tertiary education. This suggests that participants were potentially of a higher SES than the general South African population, and as a result, may not be as negatively affected by structural or logistical barriers.

6.2.4. Barrier 4: Shame and embarrassment. The fourth most endorsed barrier to help-seeking in the current study included “feeling embarrassed or ashamed”, which may link to the burden of stigma surrounding OCD as described in a growing body of literature (e.g., Glazier et al., 2015; Marques et al., 2010; Robinson et al., 2017; Williams et al., 2012).

Although stigma appeared to be a more significant barrier in other OCD studies, this result nevertheless highlights the role of stigma in living with a condition like OCD. Indeed, the problem of stigma as a barrier to seeking help is not unique to OCD, but rather is a central theme in the experience of living with a mental health diagnosis as documented in other studies (e.g., Carr & Ashby, 2020; Rüsch et al., 2005). Similarly, South African research has shown that stigma is a fundamental challenge in the delivery of mental health services (Petersen & Lund, 2011), and although anti-stigma programmes exist for mental health purposes in the country (Petersen & Lund, 2011) there is a need to assess these interventions to better understand what is effective, and to identify where the gaps are.

It is possible that feelings of shame and embarrassment may link to other factors, which are more specific to the experience of OCD. Notably, the literature has highlighted that the *content* of obsessions may be associated with the endorsement of shame-related treatment barriers (Belloch et al., 2008; Glazier et al., 2015). For example, it has been shown that individuals with obsessions that are taboo (i.e., sexual, religious, or aggressive in nature) are more likely to endorse shame as a barrier to seeking help compared to individuals with obsessions concerning orderliness or hygiene (Glazier et al., 2015). Similarly, another study highlighted that fears about the *meaning* behind obsessive thoughts plays a role in the concealment of obsessions and delayed help-seeking (Belloch et al., 2008). In this regard, it would be helpful for patients to understand that a key feature of obsessive thinking in OCD is that thoughts are generally *incongruent* with the individual's value system (Abramowitz, & Siqueland, 2013) and thus not a reflection on their character or moral positionality. Similarly, it would be valuable for patients to learn basic CBT principles regarding cognitive structures, and to gain an understanding of how dysfunctional cognitive processes become inflamed via anxiety and maintained compulsions. This level of psychoeducation would not only be helpful for patients to gain insight into their condition and encourage help-seeking, but also

for members of the general public to understand OCD better. This has the potential to minimise stereotypes and stigma surrounding the condition, which are processes that further fuel feelings of shame and embarrassment for patients with OCD.

In summary, the prominent barriers to help-seeking in this study reiterate that a range of barriers – mostly attitudinal in nature – play a central role in inhibiting processes of help-seeking for OCD in this group of South African patients. Although certain barriers may be universal to the experience of living with a mental health condition, it is plausible that some OCD-specific features (such as obsessional content) may precipitate or compound these barriers. Importantly, the challenges highlighted in this section strengthen the argument for greater awareness and education about OCD, which would mitigate stigma, secrecy and shame, and help to correct misunderstandings or myths about the condition and associated treatment.

6.3. Considerations for future research

This study is an important first step in addressing the gap in the literature concerning help-seeking for OCD in South Africa, and a number of possible future directions have emerged as a result.

Considering the help-seeking barriers identified in the current study – including shame and embarrassment, a preference for self-reliance, and concerns about treatment efficacy and costs – it may be valuable to investigate the viability of other or modified treatments, such as internet-based cognitive-behavioural therapy (iCBT), in order to mitigate such barriers. This recommendation is based on research indicating that iCBT is cost-effective and accessible, and less likely to induce feelings of shame due to reduced therapist contact (Andersson & Titov, 2014). Reduced therapist contact may also align with participants' preference to handle their problems independently. Online modes of therapy

would be conducive to OCD patients now more than ever in the current COVID-19 climate, particularly for those who have contamination fears, and/or are significantly avoidant. Thus, this is a relevant future research direction worth exploring.

A number of the help-seeking barrier themes that emerged from the current study mirror those that have emerged in other OCD studies, i.e., patients preferring to handle their problems autonomously, experiences of shame, and concerns about treatment. It is possible that these common experiences are linked to OCD-related factors, such as a tendency towards secrecy, and beliefs about the meaning and content of obsessions. Further qualitative inquiry could illuminate the context and meaning behind these experiences, thus aiding in a deeper understanding of the challenges and barriers to help-seeking among persons with OCD. By way of illustration, it could be useful to qualitatively investigate *why* the majority of participants in this sample prefer to handle their problems independently, as opposed to seeking professional assistance. Although the quantitative data in the current study effectively *identified* factors that influence the help-seeking process, qualitative research may complement and expand these findings – offering more detailed insight into how the help-seeking journey is experienced subjectively.

A key finding from the current study is that beliefs about the benefits of treatment are significant when it comes to help-seeking for OCD, aligning with a body of literature focused on help-seeking for other mental health concerns. Importantly, this highlights a call for psychoeducation in this setting, which may enhance understandings and expectations relating to OCD treatment. This could take place on an individual level within a clinical setting once patients are undergoing treatment, in order to manage expectations of treatment and endorse future help-seeking. Moreover, psychoeducation could also extend to the collective realm. Research exploring widely held beliefs about OCD in South Africa may enhance an understanding of how OCD is collectively understood, and in turn may contribute to media

campaigns or mental health literacy programmes that inform the public about OCD and its manifestations, and the evidence-based treatment options that exist. In this regard, such educational programmes may also aid in addressing help-seeking barriers highlighted in the current study related to concerns about treatment. Psychoeducation has the potential to dispel myths and untruths about OCD, with the aim of normalising and encouraging processes of help-seeking.

6.4. Strengths and limitations of the current study

This study was restricted in a number of ways. A key limitation involves the size and nature of the sample, which was relatively small and likely not representative of the general South African population with OCD. A more diverse and representative sample – involving participants from different education levels and SES backgrounds – would be helpful in understanding the help-seeking challenges experienced by the wider community. A larger sample would also have enabled the performance of more sophisticated statistical tests in addition to multiple regression analysis, such as hierarchical regression or structural equation modelling, to explore interaction effects between variables. Secondly, the study was limited by the self-report nature of the survey scales, which can be subject to bias – such as socially desirable responding, where an individual may respond inaccurately in order to present a positive image of themselves (Van de Mortel, 2008). Moreover, this study focused only on help-seeking variables that aligned with the HBM, whereas the literature has indicated that there are a range of other factors that may influence help-seeking intention – including co-morbidities, illness insight, and content of obsessions, among others (Besiroglu & Agarun, 2006; Garcia-Soriano et al., 2014; Torres et al., 2006). In this regard, it was hypothesised that prior treatment history may have influenced help-seeking intention in the current study, however, this variable was not included in the regression analysis due to its misalignment

with HBM principles. A qualitative study with a larger sample, employing a more flexible, exploratory approach with open-ended responses from participants to understand their subjective service-use experiences, would address some of these limitations.

Despite these limitations, the study had a number of strengths. A key strength is that this is the first study to address the topic of help-seeking intention in a group of South African adults with OCD, and has successfully identified local factors that may influence help-seeking for OCD in this setting. This is an important advancement towards increased awareness and understanding of the condition in South Africa, which may contribute to reduced delays in treatment seeking and ultimately in improving OCD outcome from a local perspective. In addition, participants in the study were diagnosed by a clinical psychologist with OCD expertise, using an established diagnostic interview schedule (the SCID-5). Another advantage is that the study drew on the HBM, providing a sound theoretical lens through which to conceptualise factors influencing formal help-seeking intention. This model is supported by a large body of literature spanning several decades (Carpenter, 2010). The HBM was selected as appropriate for the research aims of the current study due to its focus on predictors and barriers of service use, and its sensitivity to both psychological and contextual variables. Further, the study made use of a comprehensive and carefully designed survey, involving established and psychometrically sound scales to assess relevant HBM variables.

6.5. Conclusion

In conclusion, this is the first study to address the subject of help-seeking for OCD in a South African sample, and it has generated insight into predictors and barriers associated with help-seeking intention in this setting. Perceived treatment benefits was the only significant HBM predictor of help-seeking intention, and no significant relationship was found between help-

seeking intention and symptom severity, treatment barriers, self-efficacy, or socio-demographic characteristics. The most endorsed help-seeking barrier included a preference for handling one's problem alone, followed by treatment concerns, financial constraints, and shame and embarrassment, in that order. Although a range of barriers were endorsed, it is encouraging to note that treatment barriers did not significantly influence help-seeking intention in this sample.

The findings of this study illuminate the need for psychoeducation and mental health literacy programmes focused on OCD in South Africa, in order to educate individuals and communities about the treatment options that exist and the benefits of each, and to mitigate concerns and anxieties surrounding treatment. Further research into the subjective experiences of OCD service use in South Africa with a larger sample would enhance these findings, and aid a deeper understanding of the challenges and experiences associated with this disorder from a local perspective.

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Appendices

Appendix 1

OCD Diagnostic Criteria (American Psychiatric Association, 2013, p. 237)

Diagnostic criteria

A. Presence of obsessions, compulsions, or both:

Obsessions are defined by (1) and (2):

1. Recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress.
2. The individual attempts to ignore or suppress such thoughts, urges, or images, or to neutralize them with some other thought or action (i.e., by performing a compulsion).

Compulsions are defined by (1) and (2):

1. Repetitive behaviours (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.
2. The behaviours or mental acts are aimed at preventing or reducing anxiety or distress, or preventing some dreaded event or situation; however, these behaviours or mental acts are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive.

Note: Young children may not be able to articulate the aims of these behaviours or mental acts.

B. The obsessions or compulsions are time-consuming (e.g., take more than 1 hour per day) or cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The obsessive-compulsive symptoms are not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition.

D. The disturbance is not better explained by the symptoms of another mental disorder (e.g., excessive worries, as in generalized anxiety disorder; preoccupation with appearance, as in body dysmorphic disorder; difficulty discarding or parting with possessions, as in hoarding disorder; hair pulling, as in trichotillomania [hair-pulling disorder]; skin picking, as in excoriation [skin-picking] disorder; stereotypies, as in stereotypic movement disorder; ritualized eating behaviour, as in eating disorders; preoccupation with substances or gambling, as in substance-related and addictive disorders; preoccupation with having an illness, as in illness anxiety disorder; sexual urges or fantasies, as in paraphilic disorders; impulses, as in disruptive, impulse-control, and conduct disorders; guilty ruminations, as in major depressive disorder; thought insertion or delusional preoccupations, as in schizophrenia spectrum and other psychotic disorders; or repetitive patterns of behaviour, as in autism spectrum disorder).

Appendix 2

Recruitment email

Email addresses were included in BC (blind copy) on email correspondence, to ensure that individuals do not have the option of revealing their identities and/or responses to the email group, for example by replying to all.

Subject line: Invitation to participate: OCD help-seeking survey

Dear potential participant

You are invited to participate in a short online survey – estimated to take approximately 30 minutes – aiming to learn more about your experiences of obsessive-compulsive disorder (OCD), and how you feel about seeking professional help. If you successfully complete the survey, you can choose to be entered into a lucky draw to win a cash prize of R2000, as a reward for your time.

This study is being conducted because research has shown that many people with OCD often don't seek help for their condition, and we would like to learn more about the factors that influence this. The findings of this study will expand upon existing knowledge about OCD in South Africa, with the ultimate aim of improving access to professional help. Your participation would make a valuable contribution to this objective.

You are being contacted because you have been involved in research with us in the past, and because our database indicates that you are over the age of 18 years old, and living with OCD in South Africa. If you would like to take part in this study, your email address will be shared with the primary researcher (Sarah Hathorn) who will send you a link to the online survey. Please confirm that you are happy with this and would like to participate, by responding to this email.

Should you agree to being involved, your survey responses will be anonymised, and any personal information that you share will remain strictly confidential. This study has been approved by the Health Research Ethics Committee at Stellenbosch University.

We hope you will consider participating in this OCD research initiative.

Best wishes

Prof C. Lochner

Appendix 3

Email to participants

Dear [insert name]

Thank you so much for agreeing to participate in our study about obsessive-compulsive disorder (OCD). We are aiming to learn more about access to professional help for OCD in South Africa, and your involvement will contribute to this cause.

Your participation involves completing an online survey, expected to take you no more than 30 minutes. Your responses will be anonymised, and no personally identifiable information will be linked back to you. You will also have an opportunity to enter a lucky draw to win a cash prize, should you wish to.

Please [click here](#) to learn more about the study and complete the survey.

Thank you for your time and support, and please don't hesitate to reach out with questions.

Best wishes

Sarah Hathorn

Appendix 4

Consent form

PARTICIPANT INFORMATION AND CONSENT FORM

Title of Research Project:

Predictors and barriers to help-seeking intention among adults with obsessive-compulsive disorder (OCD) in South Africa

We would like to invite you to take part in a research project which involves the completion of an online survey. Your participation is **entirely voluntary** and you are free to decline to participate or to stop completing the survey at any time, even if you have agreed to take part initially. However, once you have submitted your completed survey online, you will no longer be able to withdraw your responses as there will be no way of linking your responses back to you.

What is the study about?

- *Research has shown that many people with OCD don't seek help for their condition. This study aims to understand the reasons behind this, and to explore the factors that may encourage (or discourage) people with OCD in South Africa from seeking help. Specifically, this study is interested in formal help-seeking, which means seeking help from a professional (for example, a GP or a psychologist, rather than friends or family). Ultimately, the goal for this study is to generate knowledge that will improve access to treatment, so that more people can receive help for OCD in South Africa.*
- *If you agree to participate, you will be asked to complete an online survey involving questions about your OCD and your experience of professional help. The survey is expected to take approximately 30 minutes in total.*
- *This study is part of a Psychology Research Master's thesis through Stellenbosch University, and is being conducted by a Master's student (Sarah Hathorn) and her research supervisors (Prof C. Lochner and Prof J. Bantjes). We are aiming to recruit at least 46 people to participate.*

Why are you being asked to participate?

- *You are being asked to participate in this study because you have been diagnosed with OCD, and because you are 18 years or older.*

What will participating in the study entail?

- *You will be asked to respond to a number of questions in an online survey. The survey will explore some aspects of your experiences of OCD, but will mainly focus on how you feel about seeking help. For example, you will be asked about your OCD symptoms, how you feel about professional psychological help, and whether you experience barriers to accessing mental health care. You will also be asked some personal information about your background (i.e. age, gender, and education level) as well as how you feel about solving problems and accomplishing goals.*
- *The survey will present you with a range of statements, and you will be asked to indicate whether you resonate with them or not (for example, you will select 'Agree' or 'Disagree').*

Will your responses remain confidential?

- *All of your responses will be kept strictly confidential, and any names, email addresses, and identifiable information will be anonymised, and will remain as such should any findings from this study be published in the future. Any information obtained in connection with this study will be stored securely, on an access-controlled, password-protected computer. We also collaborate with researchers abroad; this means we may share anonymous information with these sites to study your condition. No identifying information will be shared, at any point in time.*

Will you benefit from taking part in this research?

- *If you complete the full survey, you will be entered into a draw to win a cash prize of R2000, should you choose to enter the lucky draw.*
- *You may enjoy being a part of this initiative, and you may discover something new about how you feel about seeking professional help. You will also have the option to discuss treatment referrals at the end of the study, should you wish to do so.*
- *The findings in the study will help the researchers better understand the reasons that might prevent or enable people from receiving help for OCD in South Africa, with the aim of improving access to professional help (and treatment) for patients in the future.*

Are there any risks involved in your taking part in this research?

- *There are minimal risks associated with your involvement in this study. However, you may feel uncomfortable sharing personal information about your OCD and your feelings about professional help.*
- *Your involvement is entirely voluntary. You may withdraw from the study at any time, with no*

negative consequences.

You can contact the primary researcher on this study, Sarah Hathorn at 072 947 5365 or 16616014@sun.ac.za, if you have any questions or encounter any problems. If you experience any discomfort as a result of this study, please reach out to the research supervisor, Professor Christine Lochner at 021 938 9179 or CL2@sun.ac.za, to arrange treatment referrals.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that concerns you about how this study is being conducted, or if you have a complaint. You can **download a copy** of this information and consent form, should you wish to.

By clicking NEXT you are confirming that you are over 18 years old and have read and understood the above explanation about the study, and that you agree to participate. You also understand that your participation in this study is entirely voluntary.

[NEXT]

Appendix 5**Socio-demographic survey**

How old are you?	<ul style="list-style-type: none">• <i>[Type your age in years]</i>
What is your gender?	<ul style="list-style-type: none">• <i>Male</i>• <i>Female</i>• <i>Other [please specify]</i>
What is your highest level of education?	<ul style="list-style-type: none">• <i>No School</i>• <i>Grade 1-7</i>• <i>Grade 8-10</i>• <i>Grade 11-12</i>• <i>College / Technikon diploma / degree</i>• <i>University degree(-s)</i>

Appendix 6

Florida Obsessive-Compulsive Inventory (FOCI)

Please answer the following five questions for the following symptoms:

1) Obsessions (unwanted thoughts, urges, or images that repeatedly enter your mind (for example, concerns with contamination, with terrible things happening, with keeping objects in perfect order or arranged exactly, or personally unacceptable religious or sexual thoughts)

AND

2) Compulsions (feeling driven to perform certain behaviours or mental acts over and over again (for example, excessive or ritualized washing or cleaning; repeatedly checking or asking for reassurance; counting, arranging, or making things even or right)

(All questions refer to obsessions and compulsions over the last four weeks / past month.)

On average how frequently do these symptoms occur?	1 None	2 Mild (occasionally)	3 Moderate (often)	4 Severe (very often)	5 Extreme (near constant)
How much <i>distress</i> do these symptoms cause you?	1 None	2 Mild	3 Moderate	4 Severe	5 Extreme (disabling)
How hard is it for you to <i>control</i> these symptoms?	1 Complete control	2 Much control	3 Moderate control	4 Little control	5 No control
How much do these symptoms cause you to <i>avoid</i> doing anything, going anyplace, or being with anyone?	1 No avoidance	2 Occasional avoidance	3 Moderate avoidance	4 Frequent and extensive avoidance	5 Extreme avoidance (housebound)
How much do these symptoms <i>interfere</i> with school, work or your social or family life?	1 None	2 Slight Interference	3 Moderate; definitely interferes with functioning	4 Much interference	5 Extreme interference (disabling)

Appendix 7

Attitudes Toward Seeking Psychological Professional Help-Short Form (ATSPPH-SF)

Read each statement carefully and indicate your degree of agreement using the scale below. In responding, please be completely candid.

1 = Disagree; 2 = Partly disagree; 3 = Partly agree; 4 = Agree

If I believed I was having a mental breakdown, my first inclination would be to get professional attention.	1	2	3	4
The idea of talking about problems with a professional strikes me as a poor way to get rid of emotional conflicts.	1	2	3	4
If I were experiencing a serious emotional crisis at this point in my life, I would be confident that I could find relief with professional assistance.	1	2	3	4
There is something admirable in the attitude of a person who is willing to cope with his or her conflicts and fears without resorting to professional help.	1	2	3	4
I would want to get psychological help if I were worried or upset for a long period of time.	1	2	3	4
I might want to have psychological counseling in the future.	1	2	3	4
A person with an emotional problem is not likely to solve it alone; he or she is likely to solve it with professional help.	1	2	3	4
Considering the time and expense involved in psychological treatment, I doubt it would have value for a person like me.	1	2	3	4
A person should work out his or her own problems; getting professional help would be a last resort.	1	2	3	4
Personal and emotional troubles, like many things, tend to work out by themselves.	1	2	3	4

Scoring: Reverse score items 2, 4, 8, 9, and 10, then add up the ratings to get a sum. Higher scores indicate more positive attitudes towards seeking professional help.

Appendix 8

Barriers to Access Care Evaluation (BACE)

Below you can see a list of things which can delay or discourage people from getting professional care for a mental health problem, or continuing to get help. By professional care, we mean care from staff such as a GP (family doctor), member of a community mental health team (e.g. care coordinator, mental health nurse or mental health social worker), psychiatrist, counsellor, psychologist or psychotherapist.

Have any of these issues ever stopped, delayed or discouraged you from getting or continuing with professional care for your OCD?	Not at all	A little	Quite a lot	A lot	
Being unsure where to go for professional care	1	2	3	4	
Wanting to solve the problem on my own	1	2	3	4	
Concern that I might be seen as weak for having a mental health problem	1	2	3	4	
Fear of being put in a hospital against my will	1	2	3	4	
Concern that it might harm my chances when applying for jobs	1	2	3	4	
Problems with transport or travelling to appointments	1	2	3	4	
Thinking the problem would get better by itself	1	2	3	4	
Concern about what my family might think, say, do, or feel	1	2	3	4	
Feeling embarrassed or ashamed	1	2	3	4	
Not being able to afford the financial costs involved	1	2	3	4	
Preferring to get alternative forms of care (e.g. traditional healing)	1	2	3	4	
Concern that I might be seen as 'crazy'	1	2	3	4	
Thinking professional care probably would not help	1	2	3	4	
Concern that I might be seen as a bad parent	1	2	3	4	[5: Not applicable]
Being too unwell to ask for help	1	2	3	4	
Professionals from my own ethnic or cultural group not being available	1	2	3	4	
Concern that people I know might find out	1	2	3	4	
Dislike of talking about my feelings, emotions or thoughts	1	2	3	4	
Concern that others might not take me seriously if they found out	1	2	3	4	
Concerns about the treatments available (e.g. medication side effects)	1	2	3	4	
Previous bad experiences with professional care for mental health	1	2	3	4	
Not wanting a mental health problem on my medical records	1	2	3	4	
Preferring to get help from family or friends	1	2	3	4	

Concern that my children may be taken into care without my agreement	1	2	3	4	[5: Not applicable]
Thinking I did not have a problem	1	2	3	4	
Concern about what my friends might think, say or do	1	2	3	4	
Difficulty taking time off work	1	2	3	4	
Having problems with childcare while I receive professional care	1	2	3	4	[5: Not applicable]
Concern about what people at work might think, say or do.	1	2	3	4	
Having no one who could help me get professional care	1	2	3	4	

Appendix 9

The General Self-Efficacy Scale (GSES)

1 = Not at all true 2 = Hardly true 3 = Moderately true 4 = Exactly true

I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
If someone opposes me, I can find the means and ways to get what I want.	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
I am confident that I could deal efficiently with unexpected events.	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
I can solve most problems if I invest the necessary effort.	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
If I am in trouble, I can usually think of a solution.	1	2	3	4
I can usually handle whatever comes my way.	1	2	3	4

Appendix 10

Help-seeking intention scale

Please indicate how you feel about seeking professional help for OCD in the future. This involves any professional qualified to assist with a mental illness – such as a GP, psychologist, counsellor, or psychiatrist. If you are currently in treatment with a professional, please select 5 (very likely).

1=Very unlikely; 2=Unlikely; 3=Unsure; 4= Likely; 5=Very likely

How likely are you to seek help from a professional for OCD in the future?	Very unlikely	Unlikely	Unsure	Likely	Very likely
	1	2	3	4	5

Appendix 11

Treatment History measure

Have you received treatment for your OCD in the past?

- Yes
- No

[If yes is selected, participants are directed to the follow-up questions below. If no, they are directed to the end of the survey]

What kind of treatment have you received?

- Medication
- Psychotherapy
- Both medication and psychotherapy
- Other (specify):

What type of treatment worked best for you?

- Type your response here:

In terms of the treatments that worked best, describe the change in symptoms?

- Very much improved
- Much improved
- Minimally improved
- No change
- Minimally worse
- Much worse
- Very much worse

Appendix 12

Ethical Approval



Approved with Stipulations

New Application

10/09/2020

Project ID: 16884

HREC Reference No: S20/07/154

Project Title: Predictors of help-seeking intention among adults with obsessive-compulsive disorder in the Western Cape, South Africa

Dear Ms Sarah Hathorn

The **New Application** received on 01/07/2020 16:39 was reviewed by members of the **Health Research Ethics Committee** via Full Committee Review procedures on 02/09/2020 and was approved with stipulations.

Please note the following information about your approved research protocol:

Protocol Approval Period: **02-September-2020 – 01-September-2021.**

The stipulations of your ethics approval are as follows:

1. The budget should constitute research related expenses. Please remove the researcher's personal living expenses
2. Ensure that only participants who consented to be re-contacted will be e-mailed.
3. Please ensure that participants that do agree to participate (as requested by researcher of main study) consent that their details are given to the researcher of current study. Also include what information will be shared for example only email addresses or will other personal information also be shared.

Please remember to use your project ID 16884 and ethics reference number S20/07/154 on any documents or correspondence with the HREC/UREC concerning your research protocol.

Translation of the consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note you can submit your progress report through the online ethics application process, available at: <https://apply.ethics.sun.ac.za> and the application should be submitted to the Committee before the year has expired. Please see [Forms and Instructions](#) on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <https://www.westerncape.gov.za/general-publication/health-research-approval-process>. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics)

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mrs. Brightness Nxumalo

HREC 2 Coordinator

National Health Research Ethics Council (NHREC) Registration Number:

Appendix 13

Ethical approval: Amendment



21/09/2020

Project ID: 16884

Ethics Reference No: S20/07/154

Project Title: Predictors of help-seeking intention among adults with obsessive-compulsive disorder (OCD) in South Africa

Dear Ms Sarah Hathorn

Your amendment request dated 14/09/2020 11:17 refers.

The Health Research Ethics Committee (HREC) reviewed and approved the amended documentation through an expedited review process.

The following amendment was reviewed and approved:

Protocol Amendment #1, dated 14 September 2020

1. Minor edit of study title to 'Predictors of help-seeking intention among adults with obsessive-compulsive disorder (OCD) in South Africa' in order to include participants who may come from other parts of the country (and not exclusively the Western Cape, as proposed initially)
2. A minor change to the consent form: as the current research is a sub-study of a larger study (HREC ref no: N17/05/053) to include a line in the consent form to cover data-sharing with other researchers on the primary study, should the PI on the larger study (Professor Christine Lochner) wish to do this in the future.
3. The inclusion of a short section on treatment history at the end of the survey, in order to enrich our understanding of participants' experiences of OCD and help-seeking.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: <https://applyethics.sun.ac.za>.

Please remember to use your project ID 16884 and ethics reference number S20/07/154 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Brightness Nxumalo
Coordinator: Health Research Ethics Committee 2

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1) • REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1) • IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the

World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix 14

Thank you form

Thank you for taking part in this study!

Your responses have been saved successfully, and if you entered your email address on the previous page you will be part of a draw to win a cash prize of R2000. This study will contribute to generating knowledge about OCD in South Africa, with the aim of improving access to professional help for patients in the future. Thank you for your support and involvement.

If you have any questions or concerns about the study, please reach out to the researchers via the contact details below:

Sarah Hathorn: 16616014@sun.ac.za / 0729475365

Professor Christine Lochner: cl2@sun.ac.za / 021 938 9179

If you experienced any discomfort as a result of this study, appropriate treatment referrals can be arranged. Please reach out to Professor Christine Lochner if you would like to discuss options: cl2@sun.ac.za / 021 938 9179.